



Lived experiences and the design implications for living and dying  
with dementia in Residential Aged Care Facilities

by

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**Ethical conduct:** The Tasmania Social Sciences HREC Ethics Committee granted Full Committee Ethics Application Approval (HOO14922) to this project on 30 May 2015. The research associated with this thesis abides by international and Australian requirements and was conducted at all times in accord with the *National Statement on Ethical Conduct in Human Research*.

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**ABSTRACT***Lived experience and the design implications for living and dying with dementia in Residential Aged Care Facilities*

There has been a significant increase in age-related diseases, particularly dementia. By necessity, people with dementia spend most of their time in one setting, typically a Residential Aged Care Facility (RACF), as the requirements of care exceed the resources of most families. With increased environmental sensitivities and dependence on the environment to support their diminished cognition appropriate design of RACFs becomes a critical factor in promoting well-being.

The developing body of research on the design of environments for people with dementia is largely empirical, focused on mid-stage dementia, and on managing behavioural and clinical issues with minimal direct input from the perspective of people with dementia.

Framed by hermeneutic phenomenology, this study explores the influence of the design of RACF built environments for people living with late stage dementia. Through collaboratively interpreted stories in an immersive case study setting, it interrogates the lived experiences of people with dementia, their families, and staff.

These stories reveal the complex and at times, paradoxical construction of RACFs as both hospital and home, in addition to their unspoken and often unacknowledged role as places to die. I argue that rather than 'homes', RACFs need to be reconceptualised as hybrid places for the living and dying that anticipate and support the lived experiences of all those in the care triad. This requires the development of a new typology situated between the hospital, home and hospice and a paradigm shift in design thinking, practice, and policy aligned with the shifting landscape towards reciprocal models of care. Central to this transformation is recognition of the rights, value, and capacity of people with late-stage dementia to provide insights into their experiences of the world-of-being-in-aged-care. The sensitively designed, collaborative, and inclusive approach in this study goes some way to identifying processes and procedures to enable their meaningful participation in future research and design projects.



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## ABBREVIATIONS, ACRONYMS, AND GLOSSARY

**CEO-** Chief Executive Officer

**CSE-** Care Services Employee, previously known as Personal Care Assistant

**DSU-** Dementia Specific Unit or **DCU-** Dementia Care Unit, **DSCU-** Dementia Special Care Unit

**EOL-** End of Life

**DG-** Discussion Group

**ILU-** Independent Living Unit, i.e. residence in The Village

**IC-** Impromptu Conversation

**LTC-** Long-term care

**MMSE-** Mini-mental State Examination

**OT-** Occupational Therapist

**PC-** Prompted Conversation

**POE-** Post Occupancy Evaluation

**RACF-** Residential Aged Care Facility

**RN-** Registered Nurse

## GLOSSARY FROM *Caring for Older Australians-Productivity Commission Inquiry Report (2011)*

**Aged care-**A range of services required by older persons (generally 65 years and over (or 50 years and over for Indigenous Australians) with a reduced degree of functional capacity (physical or cognitive) and who are consequently dependent for an extended period of time on help with basic ADLs. Aged care is frequently provided in combination with basic medical services (such as help with wound dressing, pain management, medication, health monitoring), prevention, reablement or palliative care services.

**Aged Care Assessment Team (ACAT)-**A multidisciplinary team of health professionals responsible for determining the care needs and services an individual may require. ACATs are known as Aged Care Assessment Services in Victoria.

**Ageing in place-**The provision of care which allows a person to remain in their home or in the same residential care facility even if their care needs change.

**Approved Provider-**Approved Providers are organisations approved by the Australian Government, to receive subsidies for the provision of aged care services and accommodation to residents within an aged care home, or for the provision of care and services to people in the community.

**Australian Aged Care System-**The aged care system that is proposed by the Commission in this report. Services provided under this system would require an entitlement and includes personal care, nursing care, reablement services, home modification services, and planned respite. It does not include Community and Carer support services.

**Consumer-directed care (CDC)-**An approach to care that allows people to have greater choice and control over the care and support services they receive, to the extent that they are capable and wish

to do so. The concept of 'choice' in CDC varies and can include allowing people to make choices about the types of care services and benefits they access, the delivery of those services and benefits, or choice of service provider.

**High care**-The care which is provided for people who have been assessed by an ACAT (or Aged Care Assessment Services in Victoria) and need a high level of assistance with most activities of daily living (ADL). It may include accommodation services as well as personal care.

**Not-for-profit**-An organisation that does not distribute profits or surpluses to personal owners or

**Palliative care** -Care provided for people of all ages who have a life-limiting illness, with little or no prospect of cure and for whom the primary, treatment goals is quality of life. It focuses on 'living well' until death.

**Person-centred-care**-An approach to care that consciously adopts a person's perspective. This perspective can be characterised around dimensions such as respect for a person's values, preferences and expressed needs; coordination and integration of care; involvement of family and friends; and transition and continuity.

**Residential Aged Care Facility (RACF)**-Refers to facilities (other than hospitals) which provide accommodation and aged care as a package to people requiring ongoing health and nursing care due to chronic impairments and a reduced degree of independence in activities of daily living (ADL). These facilities provide residential aged care combined with either nursing, supervision or other types of personal care required by the residents. Aged care institutions include specially designed institutions where the predominant service component is long-term care and services are provided to people with moderate to severe functional restrictions.

## PREFACE

Before commencing my PhD, I had 22 years of professional experience as an architect predominantly in Tasmania, and also in New South Wales. Eight years of those years were as the director of a practice that specialised in sustainable and people-focussed design, and more particularly, projects that support people with disabilities, dementia, and ageing in place. A driving interest throughout my studies and career has been about how the design quality of the built environment can support and enhance, or undermine, well-being. Enrolling to undertake a PhD was primarily motivated by a conviction that I could make a positive difference in the lives of more people as a researcher and educator than by completing a small number of architectural projects each year. However, my return to full-time study has been far richer and more fulfilling than I expected.

While setting up my fieldwork, I was offered a Research Fellow position. I amended my enrolment to part-time to take up this opportunity. My supervisors were very supportive of my decision.

A pre-employment agreement provided a clear separation between my PhD and employment research projects. Other than the initial approval for my doctorate fieldwork, my employer, Professor XX had no involvement in this study. We did not discuss my study or correspond about the findings. The research was undertaken as an employee was unrelated to my PhD study, in different buildings, predominantly off-site at other RACFs owned by the organisation. In sum, being employed on the same site provided regular access to the research setting facilitating my aim of an immersive study in addition to affording immersion generally in the world-of-being-in-aged-care including spending time in several RACFs.

As an architect, I experienced in multi-residential care buildings that were not fit for the purpose they were designed for, particularly for those with diminished physical and cognitive capacity. Faults such as windows in a home for people with physical and brain injury disabilities with double openers requiring simultaneous winding, the lack of readily accessible toilets near the public dining room and having no provision for undercover entrance parking for picking up and dropping off residents. I visited several recently built dementia specific units with white toilet seats on white toilets against white tiled walls and highly polished white floors and densely swirled, confusing carpet patterns so that people with dementia-confused vision were unable to orient themselves and function within the spaces. These examples are in direct contradictions of the findings of 30 years of environmental research for designing for dementia.

Consequently, I was inclined to feel that my profession was largely to blame for the poor design of these buildings. By the end of my study, my perceptions of the roles and responsibilities of architects had softened, and I was able to see that the stigma and reported poor experiences within RACFs were the results of broad and complex issues.

I was particularly inspired by a courageous and generous client who I had worked with on the design of a private house to support both her husband with Lewy Body dementia and her ability to care for him. In-depth and profound discussions gave me an understanding of their lived experiences previously unknown to me. I believe it was these discussions and the qualitative understanding that went beyond a typically more functional architectural brief, compliance-based design guidelines, that lead to the success of this building in supporting both my client and her husband's subjective well-being.

I reflected on what I had learnt in my architectural practice, and particularly this house when developing my research proposal. It was clear that a collaborative design process that involved all the building users and which led to a more comprehensive understanding of people's lived



experiences could have a positive impact on the design of built environments. I believed then, as I do now, that architects have the capacity to improve the quality of people's lives through the environments they create.

My interest in death, dying, and dementia in institutional care is in part, attributable to compassion for the most vulnerable people in our community and a deep sense of understanding of well-being felt when humans have a connection with place. As I write this, I look out the window to the beautiful native forest that surrounds my home, appreciative of my sense of well-being that comes from my connection to my partner, to others, and the world, in my case, a rural setting. I realised as I struggled to explain what has brought me to this point is that some of this understanding is on the edge of my consciousness. Why then, are older people, who should be treasured and treated with respect living in some of the most uninspiring built environments in the community? Why are people with dementia, who are among the most vulnerable, unable to speak for themselves, living in poorly designed buildings when an environment of delight could positively improve their quality of life?

## **CHAPTER 1: DEMENTIA AND DYING IN THE CONTEXT OF AUSTRALIAN RESIDENTIAL AGED CARE FACILITIES (RACFS)**

### **1.1 Introduction**

Dementia is a complex illness that is often not well understood by many outside those working in fields related to aged care. While memory loss is a commonly understood symptom of dementia, often the general population does not recognise it to be an incurable, terminal disease with care requirements beyond the resources of most families (Chaudhury et al. 2017). In the later stages of the disease, many will require admission to a long-term or aged care home (Digby & Bloomer 2014). While internationally there are multiple terms for aged care homes, in Australia they are referred to as Residential Aged Care Facilities (RACF).

The incidence of age-related diseases such as dementia are set to increase dramatically in the next few decades as more Australians are reaching an advanced age (Productivity Commission 2013, p. 24). It is estimated that the number of Australians diagnosed with dementia will rise from 400,833 in 2016 to potentially up to 942,624 in 2050 (Access Economics 2011b; Brown et al. 2017).

Dementia is estimated to be the primary burden of disability for people over the age of 75 years and the second leading cause of death in Australia after coronary heart disease (Access Economics 2009; Australian Institute of Health and Welfare 2018b). As there is no cure in sight, subjective well-being and the need to support quality of life is paramount (Banerjee et al. 2006; Moyle et al. 2011).

The projected increasing prevalence of dementia as well as the growth in the population of people aged over 85, the highest users of aged care, is expected to create a shortfall of between 173, 585 and 213,000 aged care places in Australia by 2050 (Access Economics 2011a). Further, there is a predicted shortage of 98,000 informal carers in the community by 2030 (Alzheimer's Australia 2010). The compound effect is that deficits in aged care places for people over 85 could reach as high as 280,000 by 2030 and supply outstripped well before 2020 (Access Economics 2011a), requiring the construction of a significant number of new RACFs.

Significant to this study is that RACFs, however, are not highly regarded by the community, and there remains an almost universal stigma around the institutional nature (Edwards et al. 2003; Nolan et al. 2004). RACFs did not develop out of a desire to give frail older people a better life (Abbey 1995). Instead, they evolved in response to over-crowded hospitals that were increasingly unable to care for chronically unwell, older patients for extended periods particularly in Australia and the USA (Abbey 1995; Gawande 2015). While potentially solving a problem within the hospital system, the design is often driven by compliance and safety requirements, facilitating efficient care, and minimising initial capital costs (Fleming et al. 2016; Torrington 2006), with little regard for enhancing well-being and lived experiences. Further, the RACF, where many people with dementia will spend their final months of life, is not conceptualised as a place to die. Care typically remains focused on a curative medical model (Parker 2011) with implications for the design of the built environment.

Without an in-depth understanding of the influence of the built environment on the lived experience of people with late-stage dementia, and that of their families and staff, the reported dissatisfaction with the design of RACFs and community stigma will remain.

### **1.2 The research context**

Florence Nightingale wrote about the influence of the built environment on health in 1860 (Davies 2012), and the concept was embedded within Modernist architectural thinking described in the 1933 Athens Charter (Le Corbusier 1973; Sternberg 2010). While there has been more recent

growing interest in designing spaces for well-being and healing in general healthcare settings (Sternberg 2010; Ulrich et al. 2010), there has been significantly less research specific to RACFs in this field.

This point is significant because, despite Chaudhury's (2017) evaluation of gaps and limitations regarding methodology and transferability in the current body of research, there is a consensus that a poorly designed environment may have a more significant impact on people with dementia than the general population. This is due to their reduced capacity to adapt and the need for the environment to compensate for their deteriorating cognitive capacity (Parker et al. 2004, p. 941; Torrington 2007).

By necessity, people with dementia spend most of their time in one setting, particularly in the later stages of the disease trajectory (Barnes, S et al. 2002; Torrington 2007). However, there has been minimal research about end of life experiences in RACFs (Munn et al. 2008).

Førsund (2018) found that regardless of the progression of dementia, people continue to experience emotional responses through lived space and both the physical and social environment profoundly influence their lived experiences. The physical environment plays an important but often overlooked role in maintaining a connection to memories, to personhood, and significant others for people with dementia, which are being eroded by the effect of their disease progression (Chaudhury et al. 2017). Thus, the environment has a mediating role in people's understandings of their lived experiences, although this is rarely the focus of research.

The inseparable and inter-relatedness of people in the environment form the research context for this thesis. This contextual understanding of the environment contrasts with most of the research to date, which is often about individual behaviours or physical health outcomes of people with dementia influenced by specific elements of the physical building.

As such, the research to date is mostly empirical, focused on early to mid-stage dementia and on managing behavioural and medical issues (Calkins 2011; Fleming et al. 2015). There are few qualitative studies and minimal environmental research on late-stage dementia, dying or from the perspective of people with a cognitive impairment. Thus, there remains limited understanding of the influence of the built environment on lived experiences especially during the final stages of dementia.

### **1.3 Philosophical framing, aims, and structure of the thesis**

The complex nature of the inter-relatedness of the physical environment and experiences of the inner world of people with dementia anticipates a qualitative research approach that is situated, reflective, and acknowledges the value-laden nature of the research. An exploration of lived experiences also requires a methodology that is participative, inclusive, and interpretative (Laverty 2003; Miles et al. 2013).

This thesis employs the methodology of hermeneutic phenomenology, which aims to encapsulate people's meaning-making of events and their emotional relationship with place. It combines the concept of phenomenology, a study of the nature of being, with hermeneutics, a text-based analysis that involves collaboratively developed interpretations by the researcher and participants (Kafle 2011).

While other methodologies pay close attention to the framing of research questions, Smythe (2008, p. 3) argues that specific questions risk 'dehydrating' lived experiences. Hermeneutic phenomenology makes no claim that research produces objectified truths or answers to questions

(Smythe et al. 2008; Starks & Trinidad 2007). Rather it is a quest to pursue ideas and do research in a way that resonates and is a 'good fit' (Smythe et al. 2008, p. 3).

Guided by the work of Heidegger and Gadamer, hermeneutic phenomenologists argue that to understand a situated truth the researcher must embed themselves in the research context rather than attempt to distance themselves from the research participants or setting (Starks & Trinidad 2007). To this end, this immersive case study was designed to be as close as possible to the residents' ordinary everyday experiences to support their participation and allow me to enter their world.

This study aims to explore the influence of the RACF built environment on the lived experiences of people living with late-stage dementia, together with those of family and staff in order to improve the conceptualisation of RACFs in Australia.

A secondary aim was to design a sensitive research method that enables the participation of people with dementia in a way that honours their personhood, is respectful of their diminishing capacities but supports them to share their understandings of their lived experiences of being-in-the-world-of-aged-care.

Thus, this study gives voice to all in the care relationship through a reciprocal research relationship and naturalistic approach in an immersive case study. Giving voice requires the development of a way to communicate these meanings in a way that both engage the thesis reader in developing deeper understandings of being-in-the-world-of-aged-care, and also to inspire and help architects and those involved in providing RACFs to reflect on the role of the built environment on people with dementia, their family, and staff. To this end, collaboratively interpreted stories of people with dementia, their families, and staff form the core of this thesis.

The thesis begins by providing a brief context of ageing, dying, and dementia in Australia, to position the project within a historical, social, and cultural context as well as highlighting the significance of the current issues associated with the design of RACFs in relation to subjective lived experiences.

Rather than a traditional literature review and theory chapter, Chapters 2 and 3 combine a literature review with a discussion of the context of ageing, dementia, and dying in RACFs in relation to contemporary theories and competing discourses in aged care, and drivers of design in the provision of RACF built environments. With minimal research available specific to my topic, I undertook a cross-disciplinary approach drawing on areas such as dementia care, palliative care, hospice design, clinical research, and environmental research for early to mid-stage dementia, and general evidence-based aged care and health environment design.

Chapter 2 details the historical and clinical aspects of dementia before locating this study within the current context for the provision of aged care in Australia. This is followed by a discussion about the problems and social implications of the institutionalisation of dementia and dying in regards to lived experiences. Chapter 3 starts to articulate potential contradictions and incongruences between current research and design theories and practices, and the influence on lived experiences of people living, visiting and working in RACFs. Together chapters 2 and 3 provide the theoretical and research context for the study and justify the need for an in-depth understanding of subjective lived experiences from the perspective of people with late-stage dementia, their family, and staff.

Chapter 4 describes the hermeneutic phenomenological philosophical and research design approach and key theoretical concepts underpinning the study. Interpretative and reflective processes, issues

of rigour and validity, and ethical conduct of the research are addressed, and the research setting and participants introduced.

Chapters 5, 6, and 7 weave theory, literature, interpretations, and discussion together as meanings of lived experiences unfold. Chapter 5 focuses on the physical and social aspects of lived experiences within the built environment of the RACF and residents' understanding of where they are. Chapter 6 explores residents' existential understandings of everyday experiences within RACFs and their connection to the self and the 'world', and the core thread of Chapter 7 is about meaning-making about death and dying-in-the-world-of-aged-care.

Chapter 8 reflects on and integrates interpretative findings from Chapters 5, 6 and 7 to discuss how the current conceptualisation of RACFs negatively affects subjective lived experiences as well as suggesting design improvements.

The concluding chapter provides an overview of the implications of the findings for future research, architectural practice, and reconceptualising the Australian RACF in view of the expected increasing prevalence of dementia and associated problems in relation to the provision of care and architectural design of RACFs for people with dementia.

## CHAPTER 2: DEMENTIA IN THE AUSTRALIAN AGED CARE CONTEXT

Australia is facing a significant set of issues over the next few decades as indicated by the projected increased prevalence of dementia and subsequent need for admission to an RACF in the latter stages of the terminal disease as outlined in Chapter 1. This chapter provides further background about dementia, the trajectory, and need for admission and expands the discussion in Chapter 1 in relation to the Australian aged care context, concepts of ageing-in-place, and the institutionalisation of death and people with dementia in the latter stages of the disease.

Section 2.1 is an overview of dementia pathology and symptoms. Section 2.2 describes the disparity between the ideals of ageing-in-place and the reality of the high care needs of people with dementia. Section 2.3 outlines the history of the aged care system in Australia including influences on the provision of physical care environments. The institutionalisation and separation of people with dementia from the community into RACFs is critiqued in Section 2.4.

### 2.1 Dementia: the background

Dementia is an umbrella term for a complex group of diseases of the brain caused predominantly by damage to nerve cells and their connections to widespread areas of the cerebral cortex, damage to neurotransmitters and eventual grey matter shrinkage (Jacques & Jackson 2000). Alzheimer's Disease is the most common form of dementia with an estimation of 50-60% of those diagnosed, followed by vascular dementia at 20-30%, frontal temporal lobe at 5-10 %, Lewy Bodies at 5%, and the remainder having various mixed dementias (Australian Institute of Health and Welfare 2012; Jacques & Jackson 2000; Seeher et al. 2011). Different forms of dementia affect different parts of the brain causing some minor symptom variations, but all people with dementia experience an overall decline in physical and cognitive health beyond that of normal ageing.

Dementia is not a modern affliction with records referring to cognitive decline in older people dating back over 2500 years (Berchtold & Cotman 1998, p. 17). Plato, Aristotle, and Hippocrates referred to mental deterioration as inevitable in old age. While medical commentary on cognitive decline dwindled until the early nineteenth century, the concept of elderly senility as a natural part of ageing was held for centuries and is referenced in literature such as Chaucer and Shakespeare's Hamlet and King Lear (Berchtold & Cotman 1998).

With the increased interest in science and medicine in the sixteenth to nineteenth centuries, older person's cognitive impairments were considered a psychiatric disorder, and many were admitted to mental institutions. It was not until the early twentieth century that Alois Alzheimer and Otto Binswanger identified Alzheimer's Disease as an organic brain disease rather than a psychiatric condition (Berchtold & Cotman 1998; Jacques & Jackson 2000) and our understanding of the disease increased although research often remained focussed on the clinical aspects of dementia.

The early stages of the disease are characterised by progressive deterioration of memory, orientation, comprehension, learning capacity, language, and judgement (Brodaty et al. 2012; Jacques & Jackson 2000; Pearlin et al. 2001). The trajectory of the condition is unpredictable, and while it is progressive, the rate of decline can be highly variable (Mitchell et al. 2009). Following diagnosis, the reported survival time of people with dementia averages three to ten years (Brodaty, Henry et al. 2012; Kurrle et al. 2012).

While definitions of the later stages of dementia are debatable and variously referred to as end-stage or advanced dementia, the person is likely to be incontinent, non-verbal, and unable to eat independently (Abbey 1995; Jacques & Jackson 2000). Associated co-morbidities are frequent and

may include pneumonia and other pulmonary conditions, heart disease, febrile episodes, and organ failure (Brodaty, Henry et al. 2012; Mitchell et al. 2009). In many cases, people with dementia become immobile or 'vegetative', eventually leading to death (Abbey 1995; Abbey & Alzheimer's Australia 2013). Schmidt et al. (2018) posit that people with late-stage dementia suffer a range of symptoms, and their verbal communication abilities are highly restricted but that at present, little is known about their needs in the final phase of life.

Further, unlike other terminal illnesses, dementia has no clearly defined terminal stage and the need for palliative care is often not recognised until the final days of life (Andrews-Hall et al. 2007; Andrews 2010; Mitchell et al. 2009). Pinzon et al. (2013) highlight that there is often inadequate palliative care for people with dementia as there can be a failure to recognise that the resident is dying, and they are likely to have been in poor health for some time. Andrews (2010) however, argues further that the issue is that current palliative care for people with dementia remains focussed on a biomedical model centred on symptom management with minimal attention given to social, cultural, spiritual aspects, and lived experiences of people dying with dementia in part due to their limited communication skills and assumed lacking awareness.

Recent scientific and medical research has significantly expanded our clinical knowledge of dementia and understanding of the brain pathology which has assisted in symptom management and providing clinical care (Jacques & Jackson 2000). Dementia is not a normal part of ageing but is a pathological condition for which there is currently no known prevention or cure (Berchtold & Cotman 1998). As Berchtold and Cotman (1998) describe, dementia is an illness that is poorly understood outside the medical profession and seems often conceptualised by the community as communication and memory issues. Before commencing this study, my understandings of dementia were similarly limited.

Dementia is a multi-faceted illness negatively affecting physical, mental, and emotional well-being. People with dementia often suffer from anxiety, depression, confusion and can become deluded (Jacques & Jackson 2000). Particularly distressing for both the person with dementia and the family is the ongoing decline of functional and communication capacities, loss of sense of self, and ability to connect and relate to others (Chan et al. 2013). Consequently, caring for people with dementia in the later stages becomes challenging and complex (Chene 2006; Davies & Nolan 2004).

Dementia is the principal trigger of admission to institutional care (Access Economics 2011a; Australian Institute of Health and Welfare 2011a). Residential Aged Care Facilities (RACFs) provide accommodation and care for older people who are unable to continue living independently in the community. It is estimated that up to 65% of RACF residents have a diagnosis of dementia and a further 20% have a cognitive impairment (Alzheimer's Australia 2010; Productivity Commission 2013). Despite the high proportion of cognitively impaired residents, many typical RACFs have not been designed as dementia-friendly environments although there is some agreement that well-designed buildings can help to compensate for functional losses and sensory changes resulting from the condition (Fleming et al. 2016; Mahendiran & Dodd 2009).

Several authors suggest, however that sensory and cognitive impairments are neither understood nor addressed in terms of design (Chaudhury et al. 2017; Fleming et al. 2016; Ibrahim 2018). Dementia impacts a person's ability to filter and comprehend sensory experiences and environmental cues (Chaudhury et al. 2017). Spatial disorientation and an inability to way-find are relatively common, as are vision depth issues (Fleming et al. 2016).

Dementia is understood to reduce a person's ability to filter stimulation and information, or prioritise what is important or necessary, which can lead to stress when there is prolonged or excessive

sensory stimulation (Fleming and Bennett 2009). Too much visual, auditory, or aural stimulation can be challenging for a person with dementia to cope with and stressful (McIntyre and Harrison 2017). At the same time, people with dementia need cues and assistance, that is helpful stimuli in order to understand a situation or environment and minimise their confusion (Fleming and Bennett 2009). Agitation and depression can be experienced by people with dementia when an environment does not have the appropriate level of stimuli or is unfamiliar and unpredictable (Edwardson et al. 2008), especially notable following admission to an RACF and relocation from the previously familiar family home.

## **2.2 Dementia and the implications for ageing-in-place**

For most Australians, living in their own home as long as possible is perceived as desirable and conducive to quality of life (Brown, Hansnata, and Anh La, 2012; Productivity Commission 2008; Productivity Commission 2013). The concept of ageing-in-place is actively encouraged by Western governments, motivated by economic factors and congruent with community ideals of choice and independence (Nolan et al. 2006). Ageing-in-place means the capacity for any individual to safely, independently, and comfortably continue to live in their home, usually assumed to be the family home, with minimum disruption, regardless of age, financial circumstances, or physical limitation (Access Economics 2009). For a large number of older Australians, the normative expectation of ageing-at-home and living independently is a reasonable goal with more or less support from the community (Productivity Commission 2013).

A fundamental premise of ageing-in-place in the community is a reliance on a traditional family structure, which assumes the family is both available and willing to care for their older, frail relative. Fewer families, however, are expected to be available to care for and help senior people to remain living in the community (Productivity Commission 2008). Changing social attitudes and demographic trends, driven by lower marriage rates, smaller family sizes, career focus and geographic mobility, are expected to combine to contribute to a potential shortfall of 600,000 family and informal carers by 2031 (Productivity Commission 2008).

Families may not be available or wish to care for their relative (Brodaty & Donkin 2009; Duggleby 2001; Hennings et al. 2010). Many people are without family for reasons including having migrated from another country, not married, spousal death, divorce and having no children or siblings. Spouses are usually elderly and may themselves be frail (Dewing 2007; Sabat 2005), and not fit for the burden of caring for their partner or spouse with dementia at home. These demographic changes are likely to lead to an increase in the demand for RACF placements.

Further, the level of disability that characterises the mid to late stages of the disease, together with common behavioural and psychological symptoms of dementia and frequent co-morbidities, requires a level of care that is specialist and complex (Kurrle et al. 2012). While many families manage for as long as practical, there is usually a point where care requirements for a highly dependent and disabled relative are beyond the skills and resources of most families (Abbey & Alzheimer's Australia 2013). Despite familial promises, and public and government ideals of ageing-in-place, admission to an RACF often becomes unavoidable.

Family relinquishment of care is usually reluctant, particularly in the case of spousal admissions, and as a result, placement is commonly precipitated by a crisis such as a stroke, fall, or behavioural issues including wandering or aggression (Afram et al. 2014; Gaugler et al. 2001; Shanley et al. 2011). The resulting admission to an RACF is often unexpected and traumatic for both the person with dementia and their families (Butcher et al. 2001; Caldwell et al. 2014; Edwards et al. 2003).



The ideal of ageing-in-place within the family home is unrealistic for many people with dementia, but the commonly held negative image of RACFs presents a number of challenges for families and residents (Davies & Nolan 2003; O'Connor & Pearson 2004). Placement is often perceived by older people as the end of independent living, with individuals' rights subsumed by the needs of the care organisation (Nolan et al. 2004). It is often not a willing, empowered, or freely made choice (Edwards et al. 2003) but rather an inescapable result of the high levels of dependency and care required in the later stages of dementia.

The experience of placement may be fraught, with many families feeling that they are betraying their loved one (Madsen & Birkelund 2013). The family often experiences associated complex and conflicting emotions including guilt, sadness, anger, and resentment as well as at times, a sense of relief and peace of mind about their relative's safety (Reuss et al. 2005; Shanley et al. 2011).

Many families continue to care for their relative following admission but often the caring role changes to one of advocacy and surveillance on behalf of the resident (Quinn et al. 2009; Quinn et al. 2010; Sury et al. 2013). Family carers often continue to support tasks of everyday living such as feeding and dressing their relative and derive much personal satisfaction from this (Ryan & Scullion 2000). However, families often express shock about the poor quality of the RACF environment (Chene 2006; Reuss et al. 2005) and find the setting to be unfamiliar and the spaces institutional (Vohra et al., 2004). They also report feeling uncomfortable which is likely to influence the amount of time they spend within the RACF and with their relative (Stajduhar et al. 2011).

For Australian families, the predominant discourse about ageing-in-place is incongruent with the reality of the challenges of caring for a relative with dementia and the upholding of this ideal sets them up for failure (Brodaty & Donkin 2009). Family distress can be compounded by an overwhelming sense of self-reproach about placement, particularly if the quality of the RACF physical environment is perceived as low (Duggleby et al. 2013; Reuss et al. 2005).

Once admitted there is often an assumption that residents will have the security of staying in one place (Harwood & Ebrahim 1992; Small et al. 2007). People with dementia, however, are transferred from the RACF to hospital up to four times more frequently than other residents (Australian Institute of Health and Welfare 2013b; Draper et al. 2011; Peut et al. 2012), which can have significant negative implications for well-being and lived experiences.

At times, relocations are necessary to provide medical services unavailable in the RACF. However, several reports identify avoidable transfers in part due to insufficient resourcing within the RACF, including an unsupportive physical environment (Australian Institute of Health and Welfare 2013a; Digby & Bloomer 2014). Unnecessary or excessive hospitalisation of people with dementia is considered detrimental for multiple reasons, including disruption to healthcare continuity, increased likelihood of invasive medical procedures, further disorientation, and often permanent deterioration of their cognitive capacity due to the unfamiliar environment (Digby & Bloomer 2014; Draper et al. 2011; Peut et al. 2012). Relocations can exacerbate symptoms and behavioural issues including agitation, aggression, and withdrawal due to the foreign environment (Barnes 2006; Calkins 2009).

A critical area of concern in relation to ageing-in-place is the perceived poor quality of end-of-life care under the current arrangements in RACFs (Productivity Commission 2011a). 'Too often, older Australians are transferred to acute care hospitals for pain management and to die, due to insufficient expertise and resources being available in the RACF environment' (Australian Institute of Health and Welfare 2014, p. 227).

While rarely identified explicitly, there is an underlying assumption that ageing-in-place extends to include the concept of dying-in-place. Similar to notions of ageing-in-place, Australians most often express a preference to die in the family home (Abbey & Alzheimer's Australia 2013; Kellehear 2001). Despite this, recent statistics indicate that 52% of Australians die in hospital, 30% in institutions, including RACFs and hospices, and only 16% die at home (Australian Institute of Health and Welfare 2018a).

Once the ideal of dying at home has been forfeited upon admission to an RACF, it remains the expressed preference of older people to die in a familiar environment, which the residents and mainly, the family usually assumed to be the RACF (De Roo et al. 2014; Perrels et al. 2014; Volicer et al. 2003). Relocation from the RACF to an unknown and alien setting, such as a casualty or hospital ward, exacerbates family and resident stress (Australian Institute of Health and Welfare 2014). One of the greatest fears of many people about both their death or that of someone they love is that dying might occur in a noisy public ward or in an isolated room in a hospital where they may be forgotten (Worpole 2009).

Care provision, staff-family relationships, and end-of-life issues can at times be complicated and fraught due to the complexity of dementia. Families do not always conceptualise dementia as terminal with implications for their relationships and the assumptions that they make about the type of care expected and their relative's lifespan (Godwin & Waters 2009; Hennings et al. 2010; Stirling et al. 2011). Abbey and Alzheimer's Australia (2013) explains that when families can accept the inevitable and pending death, they can focus on enhancing their relative's well-being. Even when families understand that dementia is terminal, they often have unspoken assumptions that their relative is receiving palliative care and support to die within the RACF (Australian Institute of Health and Welfare 2018b; Cartwright & Kayser-Jones 2003). Families can become distressed if this does not happen, especially if their relative is relocated to hospital or experiences what they perceive to be a 'poor death' (Abbey 1995; Ryan et al. 2009).

Perceptions of a 'good death' are where dignity, privacy and personal control are maintained, pain is managed, and the dying person is surrounded by loved ones (McNamara 2001). People with dementia are rarely afforded the opportunity to express their choices and preferences about their dying process (Aggarwal et al. 2003). It is also well documented that people with cognitive and communication impairments often do not receive adequate end-of-life care and die uncomfortable and undignified deaths, representing the 'disadvantaged dying' (Brodaty & Donkin 2009).

Sub-optimal deaths are common for people with dementia and deeply distressing for the dying, the family, and staff, which demand a range of economic, social, and ethical changes (Abbey & Alzheimer's Australia 2013; Parker, D 2011). Changes are likely to include the need to reconfigure and reconceptualise both care provision and the RACF environment.

### **2.3 The Australian aged care context, dementia, and dying**

The development of institutional care for older people and the dying has a long, complicated, and difficult history (Abbey 1995). Following is a synopsis of the development of RACFs, as we know them today.

Until the 1990s, the Australian formal aged care system had evolved in an ad hoc way (Brown, Hansnata, and Anh La, 2012). Similarly, the provision of built environments was variable with few guidelines or design models. As recently as the 1990s, small private aged care facilities operated in converted large domestic homes. Many of these smaller facilities were unable to meet increasing

health and building compliance standards following the implementation of the Residential Aged Care Act of 1997 leading to larger facilities as described below.

Prior to the Act, which brought about some of the most significant structural and organisational changes to the provision of care for older people, the Australian system had 'hostels' for low care and 'nursing homes' for high care (Andrews-Hall et al. 2007). A significant reform of the Act was to integrate previously separate nursing homes and hostels into a single residential aged care system with the aim of supporting ageing-in-place so that as care needs increased, people were not required to be relocated (Andrews-Hall et al. 2007).

One of the modifications brought about by the Act most pertinent to this study was the change in terminology from 'nursing home' to Residential Aged Care Facility (RACF). The replacement of the term 'nursing home' with 'facility' was intended to remove the previous stigma associated with old-style care practices before the reforms of the 1980s and 1990s, which are now considered inhumane (O'Connor & Pearson 2004). The use of excessive sedation, physical constraints, and forced feeding, in particular, was a dark part of nursing history (Davies & Nolan 2006).

RACF is the formal term used in policy documents, organisation mission statements, marketing, and Australian academic research. The terminology and definitions for aged care settings vary internationally and throughout the environmental design literature depending on levels of care provided, funding structures, and cultural differences. Various terms in the literature include long-term care facilities (LTC), assisted living, high care homes, and nursing homes.

Parker, D (2011) and (O'Connor & Pearson 2004) contend that the terminology in Australia has added to the contradictory discourse about the role of RACFs. Parker, D (2011) proposes that the term 'facility' was intended to remove the implication for a nursing requirement, which belies the high care needs of a typical contemporary RACF population. Further, 'facility' seems contrary to the ideology of RACFs as 'home', which will be discussed further in Chapter 3. Despite the changes to formal terminology, the common use terms remain 'nursing home' or 'care home', reinforced by the language used by the family and staff participants in this study.

In Australia, aged care is predominantly provided by the non-Government sector, including not-for-profit religious, community-based, and charitable organisations. Collectively, these organisations constitute approximately 60% of placements, with 30% provided by the private sector and government-owned organisations accounting for the remainder (Australian Institute of Health and Welfare GEN Aged Care Data 2018).

Commonwealth funding subsidises the majority of placements. RACFs funded by the Australian Government must meet compulsory accreditation standards and show continuous improvement in the quality of care and services provided to residents. The Standards cover areas such as management, care, lifestyle, and safety issues (Department of Health and Ageing 2005). There are four standards and 44 outcomes to be met to achieve ongoing accreditation (Cubit 2009). The Standards include minimum requirements for the built environment discussed in Chapter 3.

The standards are considered onerous by some commentators and may have in part led to a tendency for market consolidation within the residential care sector in recent years (Productivity Commission 2011c). Fewer, but larger care providers have been purchasing and incorporating smaller organisations and RACFs (Productivity Commission 2011a). The proportion of facilities with more than 60 beds rapidly increased from 23% to 47% between 2002 and 2012 (Australian Institute of Health and Welfare 2018a). As of 30 June 2012, there were 2,725 RACFs compared to 2,961 in Australia in 2002 (Australian Institute of Health and Welfare 2018a). There has also been an increase

of 40% in the number of aged care places or beds in Australia between 2006 and 2016 (Australian Institute of Health and Welfare GEN Aged Care Data 2018).

In addition to RACFs, several aged care organisations operate 'Retirement Villages' in Australia offering 'Independent Living Units' (ILUs<sup>1</sup>) where residents may have access to community care assistance within their home (Andrews-Hall et al. 2007; Brown, Hansnata, and Anh La, 2012). Specialist dementia care is rarely offered within retirement villages, and if care needs increase beyond the means of community care provision, residents relocate to a setting providing a higher level of care, likely to be an RACF (Access Economics 2011a). The site of this study aligns with a growing trend for co-location of independent living units and high-care RACFs on the same site.

By way of further explanation, many RACFs have Dementia Care Units<sup>2</sup> (DCUs) within the facility. DCUs are likely to have been developed on the basis that smaller units support easier supervision (Reimer et al. 2004) and reduce agitation and confusion thought to be exacerbated by larger units (Fleming & Bennett 2009a). DCUs are a relatively recent innovation, and while the testimony of their benefits is mixed, a growing number of Australian RACFs and equivalent long-term aged care settings throughout western countries incorporate them (Cioffi et al. 2007).

Specialist DCUs are most commonly a wing or unit within an RACF rather than an autonomous building. The design model for DCUs is generally a small cluster of 10-20 private, single rooms with an ensuite, around a lounge and sometimes an outdoor space specifically for use by those in the secure unit.

Australia has no regulations in regards to the term 'Dementia Care Unit', and there is a wide range of facilities and types of care provided under this banner (Alzheimer's Australia 2004; Australian Institute of Health and Welfare 2012). In many cases, the staff have no additional training and several studies have found little difference in the DCU physical design, care philosophy, and training of the staff from the general RACF (McCarty 2011). In many instances, it was found that DCUs were little more than a secure unit or locked wing and sometimes, but not always, a higher staff to resident ratio (Access Economics 2009; Reimer et al. 2004).

Although numerous studies found benefits in the smaller sized, specialist units (Lee, Sook Y. et al. 2014; Zeisel, J. et al. 2003) others found contradictory evidence about the benefits of separate dementia care facilities (Cioffi et al. 2007). Slaughter et al. (2006) concluded that the primary role of DCUs is to secure difficult residents with behavioural and psychological symptoms of dementia, notably absconding, agitation, and aggressive behaviours, to protect them and other residents rather than providing tailored care (McCarty 2011; Slaughter et al. 2006). While there has been considerable research about DCUs, there has been less research and consideration of general RACFs for people with dementia.

The increasing number of residents with dementia is changing the dynamics of residential aged care in Australia (Andrews-Hall et al. 2007). As outlined in Chapter 1, the trend to support older people in their own homes for as long as is practicable means that those admitted to residential care are now older, more unwell, and more cognitively impaired than formerly (Andrews-Hall et al. 2007; Tan et al. 2013). This point of entry at a considerably higher dependency level than previously is set to

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<sup>1</sup> ILUs are self-contained house within a village-like setting. Size and ownership structures can vary.

<sup>2</sup>DCUs may also be referred to as Dementia Specific Care Units (DSCU) or Dementia Specific Units (DSU) in the literature.

continue and older people, particularly those with dementia, are increasingly expected to die in an RACF (Lee, Sook et al. 2014; Productivity Commission 2011b).

Several authors have identified systemic issues within the Australian aged care system (Andrews-Hall et al. 2007; Beattie 2009; Cubit, K 2009). The Productivity Commission reported that 'the system as currently configured cannot withstand the coming changes and fundamental reforms are required to meet changing demographics, services demand, and financial pressures' (Productivity Commission 2011c, p. xix). Care provision and accreditation is overly process-based, bureaucratic and reporting requirements reduce the time for personal care and practical tasks (Productivity Commission 2011c).

Similarly, the design of RACF buildings is overly regulated and heavily compliance based (Bennet & Fleming 2013a; Smith et al. 2012) and under-prioritises the influence of the environment on resident subjective well-being and limits the opportunity for consideration of residents' lived experiences.

Not only have many typical Australian RACFs been designed with little consideration of people with dementia, but they are also reported as notoriously under-resourced with inadequate staff-to-resident ratios for the level of care required for people with cognitive impairment (Moyle et al. 2013; Productivity Commission 2013). Care provision is discussed in further detail in Chapter 3 but of note at this point, is that there is often minimal if any dementia-specific staff training (Andrews-Hall et al. 2007; Cubit 2009).

A further disparity in the provision of care for people with dementia in Australian RACFs is a failure to explicitly recognise the terminal nature of the disease (Cartwright & Kayser-Jones 2003; Godwin & Waters 2009; Hov et al. 2013). The majority of people with dementia die within two years of admission, with 31% dying within six months and 43% within 12 months (Australian Institute of Health and Welfare 2011b). Despite the frequency of deaths, policy and regulations remain focused on a restorative and rehabilitative care (Djivire et al. 2012; Hov et al. 2013).

Care organisations typically do not perceive themselves as providers of places for the dying and customary goals are to maximise independence and improve health outcomes (Buse et al. 2016; Parker 2011; Puurveen 2008). These notions are reflected in the discourse throughout care policy documents and design guidelines, which focus on supporting independence (Productivity Commission 2011a). Concepts of 'positive ageing', 'active ageing', and 'successful ageing', linked to personal choice and independence, are also embedded throughout the culture of aged care evidenced in marketing brochures, mission statements, government reports, and economic policy.

The main problem with the focus on independence is that it takes no account of the reality of what happens for people with dementia when independence becomes an impossible goal (Dewar & Nolan 2013; Gawande 2015, p. 26). The notion promoted in policy agenda is argued by Hillcoat-Nalletamby (2014) as a limited and overly simplified view centred on functional independence suggesting rehabilitation that is at odds with a terminal illness and discounts the variability in older people's understandings of independence. She contends, however, that fostering a feeling of independence and autonomy, where one has a sense of some control over their own life, supports a sense of wellbeing at all stages of life (Hillcoat-Nalletamby 2014; Small 2007). Thus, with the support of others and an appropriate physical environment, people with late-stage dementia have the potential for a sense of self-determination and personal control despite their diminishing functional independence.

RACFs however, are not equipped philosophically or culturally to provide the sort of care that a person dying with dementia might need (Katz et al. 2001; O'Connor et al. 2013). Andrews (2010) proposes that a palliative approach to care, which focusses on enhancing subjective well-being,

should be adopted from the point of diagnosis. It follows that a similar approach is needed in the provision of the built RACF environment. Staff are generally focussed on bodily care and task efficiency, rather than end of life or palliative care (Cartwright & Kayser-Jones 2003; Hov et al. 2013) and dying continues to be omitted from the discourse beyond a biomedical discussion about symptom management (Goodman et al. 2010; Parker, D 2011), discussed in further detail in Chapter 3.

## **2.4 Dementia, dying and the phenomenon of social death**

Medical advances, changing demographics and family structures, and increasing geographic mobility have changed where we die, how we die, and how we think about death and those that are dying (Kellehear 2001; Teno 2003). Increased longevity, improved overall health, and successful treatment of previously fatal conditions are undeniable benefits of modern medicine (Gawande 2015, p. 158). The pattern of dying and our understandings of dying have been altered, and natural processes of ageing and dying turned into medical events (Gawande 2015; McGann 2013).

Rather than the common catastrophic illnesses or sudden declines of the past, dying is more frequently a long series of ever-descending declines with an irregular and capricious course (Gawande 2015, p. 159; Ryan et al. 2009). Death remains certain, but the trajectory is often longer and less predictable particularly for conditions such as dementia. The result is that there are many social, cultural, and ethical issues that we have yet to come to terms with, including as Gawande (2015, pp. 158-159) identifies, 'we are not sure what the word "dying" means anymore' rendering obsolete 'centuries of experience, traditions, and language about death'.

As society became more secular and urbanised, and the traditional family structure changed, the way society handled death also changed (Kellehear 2001). Healthcare and dying became increasingly managed by medical professionals within institutions (McGann 2013). Regardless of preferences to die at home as discussed previously, the transfer of death from the family home to institutions in western societies commenced in the early twentieth century and has become increasingly more widespread since the 1950s (McGann 2013; McNamara 2001, p. 6). Medicalisation of death, escalating reliance on technology, and the rise in chronic illness are significant drivers of the institutionalisation of the dying (Munn & Zimmerman 2006; Teno 2003).

The implications of removing people from society to die are considerable. Dying has shifted from the home where the family and individual are in control to be regulated by the state, denormalising what was previously understood as part of the natural cycle of life (Kellehear 2001; McGann 2013; McNamara 2001). Paradoxically, dying has also become a more private and isolating event that is distanced from home, everyday life, and the family. Part of the social experience of the institutionalisation of death has been the loneliness of dying (Kellehear 2001).

Several authors have described Australia as having an 'absence of a national story about dying', where we acknowledge the moment of death but not the transition between life and death, that is, the process of dying (Kellehear 2001, p. 2/11; O'Connor & Pearson 2004). Arguably, a social culture that conceals death may potentially be symptomatic of denial of death (McGann 2013).

Substantial literature argues that death and dying are one of the main cultural taboos within contemporary Western society (Lawton, J 1998). Australians' perceptions of dying are derivative of English and North American attitudes, and thus in the last century or so, as death became further removed from the everyday, we have shied away from defining and expressing ideas about dying (Kellehear 2001). Discussions focus on the technical, clinical, and institutional aspects of dying rather than the social and cultural experiences (Kaufman 2003; Kellehear 2001). Where people die and how

they die is a subject that is broached with much discomfort, and in many families is not discussed at all (Worpole 2009).

Currently, hospices are the only places that are openly accepting of the inevitability of death and are tailor-designed for dying (McGann 2013, p. 4; Worpole 2009). The hospice movement was developed in response to failings within the hospital system to provide a humane dying experience (Saunders 2001; Saunders et al. 1981). Hospital death was perceived as challenging, undesirable, impersonal, and institutional. Hospice also recognised that dying in the family home was not always feasible or appropriate (McGann 2013; Worpole 2009). The premise of hospice is both a philosophy of care that can take place in many spaces and a building with the prime purpose of supporting the dying and their families. The provision of hospice care can be in the family home, in hospitals, or stand-alone hospice buildings.

Hospice buildings are relatively small-scaled, based on a domestic home model, and designed to prioritise resident and family comfort (Worpole 2009). The emphasis is on providing familiar, calm, peaceful environments and supporting peoples' choices about living well until they die (McGann 2013).

Hospice has traditionally been associated with cancer with a relatively short trajectory of some weeks to death, and where death can be predicted with a reasonable degree of certainty (McNamara 2001, p. 122). Unlike hospice, relatively few residents in RACFs die from malignant disease (Mathie et al. 2012). The typical RACF resident tends to have chronic illnesses, such as dementia, which follow considerably more unpredictable and longer pathways to death (Mathie et al. 2012). Further, it is relatively common for imminent death to be unrecognised for people with dementia (McNamara 2001, p. 122).

Another significant difference is that the philosophy of hospice emphasises the importance of comfort in contrast to the 'hegemony in biomedical discourse' that encourages curative measures and interventions to prolong life, as well as previously discussed contradictory notions of 'fostering independence' in RACFs (Brown 2003, p. 835; O'Connor & Pearson 2004).

The concept of hospice is, however, not without issues. Scholars identify that many patients experience a sense of a loss of personhood, and removal from society sometime before their biomedical death (Brown 2003; O'Connor & Pearson 2004). The hospice offers privacy, safety, and comfort, but remains a place that is separate from home, the familiar, and the community. Similar to RACFs, patients in hospice are sequestered, and the processes of death and dying remain hidden from the everyday world of the actively living (Lawton, J 1998). Both the hospice and RACF are liminal or in-between spaces that are located in the world but not actively connected to the world.

Although I have discussed the issues of the medicalisation and institutionalisation of death generally, dying with dementia adds additional complexity. While biological death is a single event, people with dementia have been said to suffer two forms of death: physical death and a social death (Kitwood 1997, p. 8; Kitwood 1997; Zeisel 2010). As discussed, the trajectory to death for people with dementia is more prolonged than most illnesses. In the later stages, there is significant cognitive and physical deterioration including loss of mobility and communication, limb contractures and sometimes adoption of the foetal position in the final stages of the illness (Mitchell et al. 2009; Sabat et al. 2011). These symptoms have led to considerable fear, negative perceptions, and stigmatisation of those with dementia.

Social death, where people lose their personhood and are treated as if dead, takes place in tiny increments usually beginning with a person's inability to care for themselves and significantly

‘participate in the world of the living’ (Lindauer & Harvath 2014, p. 7; McNamara 2001).

Communication and cognitive capacity deteriorate to a point where there seems a barely functioning person as is expected in a world that values independence, youth, physical attractiveness, achievement, and productivity (McNamara 2001; Sweeting & Gilhooly 1997). As the person ceases to interact in a meaningful way socially, people can stop behaving as if a person is a living person exacerbating the ‘malignant social positioning’ of people with dementia (Davis et al. 2009; Kitwood 1997; Sweeting & Gilhooly 1997). Kitwood (1997) goes as far as to state that this form of dehumanisation leads to earlier biological death.

Dementia has been called ‘death that leaves the body behind’ (Kitwood 1997, p. 37), casting people into the shadowy world of ‘non-persons’ or ‘as good as dead’ (Sweeting & Gilhooly 1997, p. 87). People with dementia are treated as if they are ‘other’ and somehow lesser than the general community and then removed from the public gaze to spend their final months and die in institutional settings (Behuniak 2011; Froggatt 2001; Komaromy 2000). This geographical and perceptual setting apart strengthens the notion of ‘social death’ and the boundaries between those with dementia and those without, as well as those between the dying and the living.

It is also possible that a person with dementia can be socially dead for some people and very much alive and valued at the same time by others (Sweeting & Gilhooly 1997). While at a societal level, the person with dementia is hidden and unacknowledged, close family members often continue to care for, visit, and spend considerable time with their relative. Shanley et al. (2011) found that a form of social death can also impact families as they spend many hours in the socially separated world-of-being-in-aged-care and their own social needs subsumed by the needs of their ailing relative.

Some family members may perceive placement in an RACF as a step closer to death (Shanley et al. 2011). One of the implications of the lengthy trajectory of dementia is ‘anticipated grief’ as families adjust to the potential loss (Davies & Nolan 2004, p. 517; Hennings et al. 2010). This leads at times, to an emotional and physical withdrawal where families start to normalise their lives as if their relative had already died (Parker 2011; Sweeting & Gilhooly 1997). Some family members start to withdraw, visiting less or spending less time with their relative (Shanley et al. 2011). The loss of family negatively affects the everyday experiences and increases isolation within the RACF for people with dementia.

Given the separation from the community and alienation by some, if not all, of their own family, the person with dementia may also perceive themselves as socially dead or ‘as if dead’ (Abbey & Alzheimer’s Australia 2013). They can sometimes regard their own needs as unimportant with significant implications for their well-being (Sweeting & Gilhooly 1997). The social context of the perceived loss of value as a person further undermines physical, social, emotional, and spiritual well-being than that resulting from their pathological condition.

A large part of the knowledge about living and dying with dementia, however, is hidden from society (Kuosa et al. 2015). Research about dying with dementia is also limited, and a recent literature review about dying with dementia concluded that little is known about clinical symptom control, and even less about the lived experiences of people dying with dementia (Fleming et al. 2017).

Despite theoretical developments about valuing the person with dementia, people with dementia tend to be removed from public view, and the condition continues to be pilloried as socially unacceptable (Dobbs et al. 2008). The socio-cultural context within which death and dementia exist is primarily hidden in institutions. This not only adds to stigmatisation but limits our awareness and understandings of their lifeworld.



## 2.5 Dementia, well-being, and lived experiences

Our state of Being or being-in-the-world is a key Heideggerian concept, essentially referring to our lifeworld and our understanding of our lived experiences (Hellberg et al. 2011). Heidegger believed that an integral part of experiencing wholeness and Being is that individuals have a deep need to be in a meaningful relationship with the self, with others, with place, and with the world (Kuosa et al. 2015).

In hermeneutic phenomenology, lifeworld is understood as people's lived situation, of where we do things and relate to others, rather than merely an inner world of subjective feelings. 'It is an embodied experience where the mind, person, and world are intertwined' (Finlay 2009, p. xii; Merleau-Ponty 2012). Hermeneutic phenomenologists view lifeworlds as based in a physical world but understood through personally meaningful events, activities, lived experiences, and memories of lived experiences (Chaudhury 2003; Dahlstrom 2010).

It is the experience of our lifeworld and of connection to self, others, and place that provides the context of understandings of lived experiences and sense of well-being (Dahlstrom 2010; Finlay 2009). For phenomenologists, the experience of well-being is situational and a continuum rather than an absolute measure. It is associated with the everyday unfolding of life, alternating between a sense of familiarity and unfamiliarity in the world (Healey-Ogden & Austin 2011; Sarvimäki 2006). Well-being includes the past and present, as well as anxiety about death and the unknowable future (Banerjee et al. 2009; Sarvimäki 2006). While people with dementia have been found to be less expressive of joy, interest, and sadness, their fear and anger responses remain active (Clare 2010).

Thus, well-being as a phenomenological concept refers to a subjective experience rather than a clinical view of health or measurable quality of life. Lawton, a pioneering researcher in this field, views well-being as a multi-dimensional concept for people with dementia consisting of the objective environment, behavioural competence, including health, perceived quality of life, and life satisfaction, all of which influence and are influenced by each other (Antonovsky 1996; Lawton 1997; Sarvimäki 2006, p. 5).

While well-being, quality of life, and health are used interchangeably in the academic literature and by the public, there remains no precise definition of well-being (Beerens et al. 2013; Ettema, Dröes, et al. 2005; Ettema, Droe, et al. 2005; Fleuret & Atkinson 2007). Quantitative concepts of well-being tend to relate to clinical measures of physical or mental health, but phenomenologists argue that this is not a real indicator of what it is to be a whole human being (Sarvimäki 2006). Further, objective methods do not consider the 'disability paradox' where people can experience well-being in the face of illness or physical losses (Albrecht & Devlieger 1999; Carr et al. 2001).

As discussed previously, dementia has a negative impact on physical and mental health as well as subjective well-being. The pathology that causes the loss of memory, cognitive ability, and language also challenge the ability of people with dementia to maintain a connection with the self, others, and the world (Hellström et al. 2005; Tappen et al. 1999). For Heidegger, connectedness relates to the fundamental and universal human need for a sense of belonging (Håkanson & Öhlén 2016; Milligan 2003; Smythe et al. 2008).

Significant in the literature is that family relationships have been found to not only be the primary source of well-being for people with dementia but are also vital in supporting their ability to remain connected with their disease-induced diminishing sense of self (Brown Wilson 2009; Kuosa et al. 2015). As their illness progresses, it becomes increasingly more difficult for a person with dementia

to maintain connections independently, and they need the support of meaningful others (Håkanson & Öhlén 2016; Kuosa et al. 2015; Merz & Huxhold 2010).

The need for support from others, especially given the centrality of family relationships for well-being, is a crucial consideration in light of reports that families feel unwelcome in the RACF environment (Chene 2006; Stajduhar et al. 2011). Further, poorly designed and impersonal environments may contribute to family and resident perceptions of poor quality of care (Kuosu et al. 2015).

Several researchers found that being able to experience the familiar had a positive impact on a person's sense of belonging and sense of self (Chaudhury, H et al. 2017; Kuosa et al. 2015). Ohlen et al. (2014) found that the experience of belonging in a place was related to the experiences of wholeness and of being connected to one's past and future.

Personalised environments have been shown not only to be beneficial in slowing down intellectual deterioration and improving social interaction but also to facilitate a sense of belonging in a place (Chaudhury 2008; Zeisel et al. 2003). Being surrounded by personal objects can support people with dementia to maintain their identities (Kuosu et al. 2015), encourage them to participate in meaningful activities (Örülöv 2010), and support feelings of recognition of oneself in the environment (Edvardsson et al. 2008).

The physical environment plays an essential but often little-recognised role in enabling people to hold on to memories through association to place (Dovey 1985). Places are integral to the understanding of personal identity, the formation of memories and the construction or reconstruction of one's life history and the story of the self (Chaudhury 2008; Wollan 2003). This relationship to place is potentially even more important for people with dementia who are struggling to maintain a sense of self than for the general community (Atkinson 2013; Atkinson et al. 2012; Williams 2002).

Place has been found to influence and partly constitute identity (Gallagher 1994; Malpas 2012, 2014). Malpas (1999) draws on philosophical ideas of identity and recognition of self to argue that people's self-expression and perception of self is intimately bound to place, often to places where they reside or may have resided in the past. Place is deeply woven into human experience, and place identity is understood to be the construction of self in the world, where a sense of belonging and meaning in life is developed through a personal attachment to place (Williams 2002). Place attachment or 'place-identity' is often experienced as a sense of being 'at home' (Dovey 1985; Ohlen et al. 2014). In a study by Williams (2002, p. 145) participants described this experience as being comfortable, familiar, and 'really me' in a personally meaningful place.

A sense of continuity between the past and present may provide the framework that grounds and supports a potential future sense of self (Chaudhury 2003; Chaudhury & Rowles 2005; Smythe et al. 2008). Without a connection to places that hold memories, people with dementia can potentially become anchorless (Chaudhury 2008). Difficulties in connecting the present situation to previous experiences as well as to future expectations may lead to a 'fragmented experience of the world and the self' (Healey-Ogden & Austin 2011; Örülöv 2010), to feelings of being 'homeless' (Dovey 1985) or lacking in a sense of stability of the self (Moore 2000, 2007).

Meaning, value, and significance are more present in environments that have a strong sense of place (Williams 2002). Emotionally significant places like home can retain meaning into the later stages of the dementia trajectory, potentially enabling an ability to connect with the self and with others (McLean 2007). Personally significant places and memories associated with meaningful places can

become even more highly valued when the individual is situated in a place where they feel disconnected (Williams 2002).

Memories with feelings associated with places that have a strong emotional attachment may also be more accessible than other memories (Chaudhury 2008; Malpas 2012). For many people, their most robust attachment is to the family home where they may have felt the most secure and safe. Place shapes our memories and emotional experiences; we understand our emotions and memories of lived experiences through place (Chaudhury 2003; McLean 2007). Thus, place is at the core of remembered lived experiences, which are interpreted and re-interpreted so that meanings evolve indefinitely (Chaudhury 2008, p. 21).

Spaces, including home spaces, do not have inherent meaning; they are simply a physical container. We give them meaning and people form place attachments over time through emotional responses to perceptions of events, and cultural and social understandings based on memories of lived experiences in those places (Chaudhury 2008, p. 13). Chaudhury (2003) proposes that place attachment can be a function of the extent to which an environment supports one's needs and preferences.

In the case of people with dementia in RACFs, it is likely, therefore, that an inability to form a place attachment negatively affects well-being and a sense of belonging. Upon admission to an RACF, people with diminished adaptive processes due to their illness must renegotiate their emotional experiences (Davidson & Milligan 2004; Milligan 2003).

Our preferences for some places and those we give personal significance are formed through our perception, cognition, action, affect, and meanings we make of those places. 'These aspects of place experience are fused in forming the core of place experience that over time develops into "sense-of self-in-place", an intangible part of self-identity, which reflects the experiential aspects that relate to, and as a result become part of the self' (Chaudhury 2008, p. 13).

Neurological damage resulting from their condition often leads to people with dementia feeling lost in a strange and unfamiliar world (Holst & Edberg 2011). Their disorientation and disconnection can be experienced as both existential and social (Örülöv 2010). If people are unable to make meaning of places due to the qualities of spaces that are unrelatable to known places or experiences, the likelihood of loss of self is increased.

Moreover, several authors propose that long-term care facilities often afford few links with residents' personal or cultural past (McLean 2007; Österlind et al. 2017). Örülöv (2010) found the person might have severe difficulties in placing him or herself within the RACF. Typical social and physical aspects of the care setting usually reflect institutional policies and procedures as opposed to the personally meaningful place the resident has left behind (Chaudhury 2003).

## **2.6 Discussion**

Helping people with dementia to find a way of placing themselves in the RACF in a way that affords a positive self-identity and continuity with their life history, as well as a sense of belonging is a major challenge, but little research has been completed in this area (Örülöv 2010).

On a positive note, due to their increased environmental sensitivity, even small improvements in building design quality can have a disproportionate increase in the sense of subjective well-being for people with cognitive deficits, benefitting interpersonal relationships, and positive lived experiences (Calkins 2009; Torrington et al. 2004). Consequently, there is value in developing further understanding of the influence of the built environment on lived experiences.

This chapter commenced with the clinical context of dementia to provide an understanding of not only how the progressive symptoms of the disease affect physical and cognitive capacities, but also the social and existential impacts of the disease. Widely held ideals of ageing-in-place were shown to be problematic for people with dementia, not only in the family home but also in the RACF where numerous detrimental transfers to the hospital can occur. A critical issue discussed was that RACFS had been poorly conceived as places for people with dementia or as places of death despite the changing dynamics due to delayed admissions and increased frailty of the RACF population.

For people with dementia, the relocation into an RACF resulting from their high care needs may be experienced as particularly traumatic as they are not only losing a sense of themselves through their pathological condition but have now also been displaced from their previous familiar world and sense of belonging (Milligan 2003). The relocation or dislocation also disturbs their sense of connection with the self and with significant others.

Both the disease of dementia and death are uncomfortable topics for many people in contemporary society, argued to be in part due to the removal of the frail and dying from public view and sequestered within institutions. While Chapter 2 has focussed on the impact that this has had on lived experiences and a sense of well-being for people with dementia, Chapter 3 explores the relationship of our attitudes and understandings of dementia regarding philosophies of care, and the conceptualisation of RACF built environments.

### CHAPTER 3: FROM PATHOLOGY TO PEOPLE- A PARADIGM SHIFT?

Chapter 2 outlined the pathology of dementia, the need for admission, and the context of Australian RACFs, including some of the known challenging implications of the institutionalisation of dementia and dying for residents' well-being and sense of place. Chapter 3 extends the discussion about Australian RACFs to include current ideologies and research model about the provision of care and accommodation which remain focussed on symptom management, often at the expense of subjective wellbeing and lived experiences.

The importance of the influence of building design on subjective lived experiences and the noteworthy environmental sensitivity of people with dementia was introduced in Chapter 1. This chapter briefly discusses contemporary paradigms of care and starts to explore how the focus and intention of design may affect the lived experiences of people living and dying with dementia. Concepts of care are widely debated in health-related academic circles, and in-depth analysis is beyond the scope of an architectural thesis.

Section 3.1 outlines the practical challenges in providing care, which is questioned in relation to changing theories of care, in particular, Person-Centred Care (PCC). Section 3.2 explores the concept of PCC, interpreted by some designers and theorists to mean '*homelike*', and the potential limitations in current understandings when applied to the design of RACFs. The arduous regulatory system and objective approach to the design and production of RACFs that is at odds with the values of PCC and supporting positive lived experiences are discussed in Section 3.3. Section 3.4 discusses what are understood to be 'best practice' design approaches and their limited application in the design of Australian RACFs. Section 3.5 critiques the empirical base and other limitations of current research in relation to a Heideggerian understanding of the experience of space. Section 3.6 concludes by summarising the gap in knowledge that this study intends to fill including the lack of understanding of lived experiences in late-stage dementia, the failure to consider death and dying or the needs of all in the care relationship in the design of RACFs. This chapter establishes the need to adopt a situated, hermeneutic phenomenological approach that directly includes people with dementia, their families, and staff directly in the research.

#### 3.1 Medical model to Person-Centred Care: a new way of thinking?

In nursing history, the value of older persons as individuals, particularly those in large institutions, was not considered and care was based on rigid rules and task orientation that served the organisation rather than the people (McCormack 2004). The centrality of care was person-as-body, a body that required washing, dressing, feeding, and moving around the care home in accordance with the schedules and routines of the institution rather than the needs of the residents who were rarely given the opportunity to express their choices and preferences (Aggarwal et al. 2003; Dewing 2002; Moyle et al. 2013).

Care was conceptualised within the medical model as the management of the pathological symptoms of the disease, rather than care of the person (Beattie 2009). People with cognitive impairment were viewed as 'patients' with problematic behaviours and a medical condition which required managing (Aggarwal et al. 2003; McCormack 2002). The emphasis on tasks and physical care was at the expense of valuing the whole person and their individual physical, emotional, and spiritual needs (Abbey & Alzheimer's Australia 2013; Kitwood, T 1997).

While it essential and humane to alleviate the symptoms of any illness, particularly those that induce pain or distress, the clinical framing of care which over-privileges symptom management was at the expense of personhood. Although a medical model of care pervaded healthcare generally, care of

people with dementia was often more depersonalising than for most of the population who were more able to exercise some control over their lives (Dewar & Nolan 2013).

Negative attitudes towards people with dementia and dehumanising practices prevailed for many decades until the seminal work of Kitwood and Lawton challenged the depersonalising effect of the medical model of care, which they argued further contributed to a decline in cognitive capacity and well-being (Bredin et al. 1995; Lawton 1997; Zeisel 2010). Rather than solely a result of their illness, the loss of personhood and sense of self argued as an outcome of the way people with dementia were treated as 'less than human', objectified, and not valued as individuals (Behuniak 2011; de Vugt & Dröes 2017; Kitwood, T 1997).

Lawton, an early environmental gerontologist, stated that values such as dignity and privacy are an 'inalienable right' (Lawton 1981, p. 245). He promoted the need to focus on subjective well-being and understood the importance of the complex person-environment interaction on well-being (Lawton 1977; Pearlin et al. 2001). Kitwood, T (1997) developed the concept of Person-Centred Care (PCC) that was based on valuing the person and providing personal choice and autonomy. The contributions of these scholars were significant in reframing western thinking about people with dementia and informed both scholars and the aged care culture in recent decades.

Valuing personhood became a central tenet and the key goal of nursing and care practice (Dewing 2004) although the concept of 'personhood' is complex and contentious and with various interpretations within health-related academic circles (Higgs and Gilleard, 2016). PCC is based on staff connecting with and getting to know the residents personally so that care can be tailored to the needs of the individual (Ortigara & McLean 2013). The intent of PCC is that each person is free to make choices regardless of their impairments (McCormack 2004). Thus, PCC is a moral position that protects the rights of individuals, respecting their value as a person and their dignity.

The PCC model is viewed by many as the 'gold standard' of dementia and aged care (Beattie 2009; Moyle et al. 2013). There is little doubt of the positive impact made by Kitwood with his concepts of personhood capturing the intrinsic worth of persons, which provided a new sense of purpose for care staff (Moyle et al. 2013). The concept of valuing personhood is a fundamentally noble ideal, representing a universal 'moral principle that extends beyond politics, religion, wealth, privilege, cognition, rationality, or ability' (McCormack 2004, p. 33). Higgs and Gilleard (2016) however, maintain that terms such as 'personhood' are unhelpful concepts to underpin models and standards of care as they are too abstract and not clearly understood.

PCC was a significant move from 'pathology to people', and there is widespread support of this concept, although the philosophy of valuing personhood does not always translate into practice (Dewar & Nolan 2013; Nolan et al. 2006). PCC is not without issues, especially within the current context of performance-based care and inadequate resourcing to care for highly dependent residents (Dewing 2004). As discussed in Chapter 2, RACFs are reputedly under-resourced for the demands of caring for people with dementia and several detractors argue that PCC has added complexity and created tensions within organisations (Dewar & Nolan 2013; Fazio et al. 2018; Nolan, M et al. 2006).

McCormack (2004) concludes that despite the long-term inclusion of PCC in policy, public discourse, and research literature as a concept, there is little empirical evidence articulating the benefits and organisational perspectives of implementation. Several scholars are critical of the concept of PCC regarding care delivery when definitions are inconsistent and specific dementia care training is often non-existent (McCormack 2004; Moyle et al. 2013; Ortigara & McLean 2013). Popham and Orrell (2012) found that even when the staff knew about PCC, it was seen as an ideal rather than a realistic

goal. Management practices and organisational structures often remain focused on task efficiency and care of residents' basic physical needs (Aggarwal et al. 2003; Moyle et al. 2013).

Critics argue that PCC can be conceptually limited and is a somewhat misguided and overused term that has lost some of its original value and intent (Adams 1996). As a result, PCC has become part of what Nolan et al. (2004, p. 46) refers to as 'contemporary speak,' which he critiques as a 'heroics' model that fosters notions of independence and privileging autonomy that is unrealistic and potentially undesirable for people with ongoing declining health and cognitive abilities.

Further, several researchers caution that we must be careful not to be driven by the model and the 'ideal of personhood' but strive for a more general humanist approach in everyday practice (McCormack 2004; Nolan et al. 2006). While respect for personhood is fundamentally about supporting well-being and overcoming the issues of the previous task-oriented care model, PCC continues to position the cognitively impaired person as a passive receiver of care (Nolan et al. 2004). Thus, PCC risks marginalising other people in the care relationship as it focuses on the benefits of the care relationship for the person with dementia, notionally rendering both family and staff roles as peripheral (Nolan et al. 2004; Nolan et al. 2002).

Caring is a complex process, and there are many factors, including the built environment, which influences the quality of care and relationships between residents, family, and staff. As discussed in Chapter 2, supportive relationships with significant others and remaining in a familiar environment have been identified as the most critical factors in determining the quality of care and supporting well-being for people with dementia (Davies, S & Nolan 2006; Fleming & Purandare 2010; Hadjri et al. 2012).

In response to the issues identified with PCC, a model of care has been proposed that is predicated on reciprocal relationships (Nolan et al. 2002; Smith et al. 2010). The concept of well-being promoted by reciprocal care relationships expands the notion of PCC to include people in the caring relationship: the person with dementia, the family, and staff. Reciprocal relationship-centred care is more inclusive and recognises that the caring relationship has benefits and meaningfulness, as well as strains, sacrifices, and challenges for all parties.

Further, and crucial to this study, is the conclusion of Dewar and Nolan (2013) that interconnected reciprocal relationships are situated within an inter-related social and physical environment. The ideal relationship is based on an appropriate balance of independence, interdependence, and dependence supported within the social and physical setting. Reciprocal relationship centred care is based on the Senses Framework developed by Nolan and colleagues to provide an enriched environment of care so that the six senses of security, significance, continuity, belonging, purpose, and achievement are experienced by all in the care relationship; residents, family, and staff (Nolan et al. 2006; Wilson et al. 2013).

The reciprocal care model is in the early stages of research and implementation in care organisations, and Dewar and Nolan (2013) acknowledge that further development and evidence is required. While a more detailed discussion is beyond the scope of this thesis, the core mission of valuing all in the care relationship inspired and informed the research approach taken in this study, as described in Chapter 4.

### **3.2 PCC, 'homelike,' and at-homeness**

The issues in understandings and the implementation of the PCC model of care discussed above are similar when the PCC model is applied in environmental research and the design of buildings for

people with dementia. Edvardsson et al. (2008) argue that little is known about how the provision of PCC influences the design of the built environment, and definitions regarding RACF settings are vague and inconsistent.

PCC is often interpreted to mean the provision of '*homelike*' settings (Fleming & Bennett 2009b; Verbeek et al. 2009). '*Homelike*' is an often misinterpreted and poorly understood concept (Barnes et al. 2002; Fay & Owen 2012; Fleming et al. 2017; Innes et al. 2011). Fleming et al. (2017) state that definitions of 'home' have come from a variety of academic and professional disciplines and is a dynamic and complex concept. Designers have often construed '*homelike*' to mean a small-scaled residential unit (Brownie 2011), a small number of residents (Davis et al. 2009) or spaces that provide for everyday domestic activities such as cooking and washing dishes (Cutler & Kane 2009; Hadjri et al. 2012; Rijnaard et al. 2016). '*Homelike*' has also come to be interpreted by care organisation managers and designers as the solution for '*non-institutional*' design. According to Calkins (2009), the problem with the common linguistic practice of describing what something is not in a design brief assumes the designer knows what quality is aspired to and that the whole profession will know and agree on what '*non-institutional*' or '*homelike*' means.

The application of '*homelike*' characteristics is often employed in an attempt to recreate a sense of 'home' within the RACF. A key issue identified with the metaphor is that *home* means different things to different people, and meanings can change as people age (Rijnaard et al. 2016; Varley 2008). Multiple meanings exist within the literature (Fleming et al. 2017; Moore 2007). As van der Horst (2004) concluded there also is little consensus on definitions or meanings of home in academic circles although there tends to be a focus on home as a place of personal choice and control. Several scholars consider the concept 'dangerously vague' and sentimental, risking 'ambiguous, nostalgic, and regressive' interpretations (Mallett 2004, p. 47; Varley 2008). The mythology of 'home', often idealised as a putatively stereotypical family home, has limited our understanding of the 'complex and multi-faceted phenomenon' of 'home' (Manzo 2003, p. 56; Moore 2000, 2007) and rarely includes discussions of potential cultural and gendered understandings of home (Harraway 1988).

Despite the lack of clarity, '*RACF as home*' has come to symbolise an ideal or an aspiration in aged care (Parker 2011). The metaphor is applied in several contexts including design briefs, standard design guidelines, government reports, and promotional material (O'Connor, M. & Pearson 2004). There is a risk that paradoxically prescriptive, yet vaguely defined guidelines, generate a response that superficially addresses the notion of '*homelike*' to meet minimal aged care accreditation requirements and organisational marketing purposes, without an understanding of what 'home' truly means to individuals.

Much of the environmental design research focus on home as a physical building and emphasises an idealised aesthetic that overlooks deeper meanings of *home* (Moore 2000, 2007). Token elements of a familial home are inserted into larger institutional buildings effectively producing what Fay and Owen (2012, p. K/32) term a 'decorated living room'. The often-superficial use of domestic furniture and paintings is out of scale and place in large institutional spaces (Calkins 2009). This approach, together with medication dispensaries, pan-rooms, long corridors with non-slip surfaces and the overwhelming smell of cleaning products, results in RACFs which remain undeniably institutional in appearance and feel (Calkins 2009; Torrington 2007).

Several studies found that despite residential-scaled furniture and curtains, the large scale of the dining room and the the number of tables shared with strangers led many residents in long-term care to believe they were in a café (Chaudhury et al. 2013; Torrington 2006). This resulted in a



reduced calorific intake, as they thought they had to pay for their food, with some becoming further distressed, as they did not have any money (Torrington 2006).

Home is more than a physical place. It represents a multi-dimensional concept and a western cultural ideal that can fulfil many needs including a legal concept of ownership as well as a philosophical sense of belonging, and a source of connection to identity (Cooper-Marcus 1995; Moore 2007). Home provides a rootedness in a changing world, providing financial, emotional, and psychological security for many people (Cooper-Marcus 1995; Fleming et al. 2017). 'Home' is for many a positive place, notwithstanding that the family home can be unsafe, and a place of burden, violence, powerlessness, oppression, and isolation, notably for some women (Haraway 1988).

For most people, home as a place of security and belonging is a particular spatial experience that is essential to our sense of well-being and connection to the self and others. Much romanticism is centred on home as a 'haven,' or 'retreat' from the outside world suggestive of a place where one can escape (Cooper-Marcus 1995). Home conceived as shelter and territory supports well-being, but the current stigma and associated reluctance to be admitted to an RACF is not suggestive of a peaceful refuge (van der Horst 2004) or a place to '*dwell*', which is a central tenet of Heidegger's philosophy (Heidegger 1962; Heidegger & Hofstadter 1971; Hellberg et al. 2011).

The home, as is commonly understood, is a private space as well as the predominant space for relationships with significant others. We think of the home as a place of autonomy where most individuals have the power to choose whom to welcome or not (Milligan 2003). While the experience of autonomy is not always explicitly understood when in the family home, the loss upon admission to an RACF is deeply grieved (Cutchin 2009). The residents of RACFs now reside communally with strangers rather than family and must conform to procedures and schedules of the organisation (Van Steenwinkel et al. 2017).

Much of our familiarity and derived comfort is rooted in routines, habits, and activities of daily living established over many years, and carried out with ease of repetition and muscle memory of the space where we have been dwelling (Dovey 1985). A typical example is how we find our way to the bathroom in the dark, successfully navigating the furniture and other obstacles through embodied familiarity and habit (Dovey 1985).

This predictability can enable a person with dementia to maintain an apparent reasonable level of functioning and self-care and to develop coping mechanisms that assist them in continuing to live independently well into their illness progression (Aminzadeh et al. 2009). Families have often expressed shock at what appears to be a sudden decline in physical functioning upon admission to an RACF and increased disability once removed from the enabling space of their own home (Aminzadeh et al. 2009). The loss of familiarity, however, not only negatively influences their operational performance, but also their sense of being in a known and understood world.

For Heidegger, '*dwelling*' was deeply entwined with how it is to be human in the world, how we make meaning of our world, and how we are in the process of 'becoming' (Heidegger 1962; Moore 2000). To '*dwell*', humans need a familiar place in which they can live freely, to feel 'at home', relax, and feel that they can be themselves (Van Manen 1990). '*Dwelling*' is a way of being-in-the-world where people connect in meaningful ways with others and the world as a whole (Heidegger 1962).

For hermeneutic phenomenologists, our primary goal, whether consciously understood or not, is to move towards a place of dwelling (Heidegger 1962; Hellberg et al. 2011). In this regard, home and '*at-homeness*' become a verb, something we strive to do rather than a noun or a physical construction (Mallett 2004; Manzo 2003; Ohlen et al. 2014).

Phenomenologists' conceiving of the need for '*dwelling*' as a fundamental characteristic of the condition of being human is closely related to '*at-homeness*' (Harries 1997; Zumthor 2006b). They argue for an archetypal home as a place where we experience '*dwelling*', suggesting a potential to create a sense of '*at-homeness*', and qualities of home in a variety of settings other than the family home (Manzo 2003; Rijnaard et al. 2016). Rather, '*at-homeness*' and '*dwelling*' are viewed as existential states conjuring up for each individual their own personal notion of the meaning of 'home' and what it is to feel '*at-home*' (Manzo 2003; Moore 2000). In this way, '*dwelling*' is the experience against which we measure and try to make meaning of all other lived experiences

For most of us, 'home' infers familiarity, personal control over the environment and a place of memories and personal history (Israel 2003; Varley 2008). Cooper Marcus' (1995) notion of 'home' as a vessel of memories is an important concept for this study of people who are suffering memory loss and an associated diminishing sense of self. The family home is often the setting of past significant events and social activities. The choice of physical objects and displayed personal belongings are often related to those events, particularly photographs or gifts, providing continuity and a reminder of a person's past (Chaudhury 2008). Personal objects hold an emotional value as well as providing decorative value that helps to create a look related to home (Rijnaard et al. 2016).

A function of the space available to residents within an RACF is that admission involves a shearing of a person from their personal belongings (McDonald & Turner 2011; Rubinstein 1987). The move is often a sudden severing of a person from all that they are familiar with and from the place where they felt they belonged (Van Steenwinkel et al. 2012).

Both making a home 'their own' and developing a sense of feeling '*at-home*' are processes that take place over time (Schillmeier & Heinlein 2009; Van Steenwinkel et al. 2012). Termed by several authors as 'appropriation', it is where we make our mark on the physical dwelling space, which we often do through our belongings (Chaudhury & Rowles 2005; Cooper-Marcus 1995; Van Steenwinkel et al. 2012).

It is often in the family home where we surround ourselves things that we value, and how and where we place our collection of things that creates or invokes an individual sense of 'home' and belonging (Ohlen et al. 2014; Van Steenwinkel et al. 2012). Cooper-Marcus (1995, p. 4) proposes that the home is the only place in the world where many people can freely express themselves, and the choices that we make are a 'mirror' of who we perceive ourselves to be or are striving to become. 'Home' and self-identity are deeply entwined and inseparable, and this is often made apparent to others through the compatibility or integrity of the objects we allow into in our home (Zumthor 2006a). Thus, we use our belongings, and the ways we choose to furnish and decorate our home to make it feel like it belongs to us as well as being a reflection of ourselves.

The home space anchors people within a particular locality yet is a daily reminder of our past, providing continuity with our previous and present self, and our relationship with others (Milligan 2003). In this way, the symbolism of home not only connects people with dementia to their sense of self and their history, but it can also facilitate a sense of belonging in a neighbourhood, a community, and the world (Førsund et al. 2018). Our bond with home is intellectual, conscious, and real, but it is also primal and unconscious, 'reflecting the adage that home is where the heart is' (Dovey 1985).

Several qualitative studies have found, however, that many people with dementia did not identify with the RACF as their home (Innes et al. 2011; Schillmeier & Heinlein 2009). Instead, their experience of the RACF has been variously reported as 'displaced' (Rasmussen et al. 2000), disoriented (Örülöv 2010) and 'unsettled and homeless' (van der Horst 2004). This is not the intention

of those that produce and provide RACFs spaces, but the result of the current conceptualisation and design of RACFs.

### 3.3 Drivers of the design of Australian RACFs and lived experiences

While there is often a vaguely defined requirement with design briefs and guidelines for RACFs to be '*homelike*', the drivers of design contradictorily are primarily minimal compliance, safety, risk management, minimising capital costs, and arduous regulatory requirements. The focus of design of RACFs in Australia has little relationship to the concept of buildings designed to enhance subjective lived experiences of people living and dying with dementia, their family, or staff.

Numerous regulations drive the design of Australian RACFs. They must comply with the Building Code of Australia (BCA) (Building Code of Australia 2013) and the Building Quality for Residential Aged Care Services: Certification (Australian Dept. of Health and Ageing 2005) as well as meet aged care accreditation requirements.

The BCA defines an aged care building as 'a building for residential accommodation of aged persons who, due to varying degrees of incapacity associated with the ageing process, are provided with personal care services' (Australian Dept. of Health and Ageing 2005; Building Code of Australia 2013, p. 32). The BCA regulates the quality of building fabric covered under the following sections, none of which includes any qualitative design requirements: Fire Safety and Resistance; Access and Egress; Services and Equipment, Health and Amenity, and Energy Efficiency (Building Code of Australia 2013). Furthermore, under the BCA building classification system, RACFs are Class 9 buildings, that is, buildings of a public nature, requiring the highest level of safety and construction standards.

In addition to the BCA, all RACFs receiving Commonwealth aged care subsidies must meet requirements assessed under the Building Quality for Residential Aged Care Services-Certification which dictate minimum standards for resident safety and amenity (Fleming, R et al. 2008; Hunter & Elkington 2005). As the Australian government subsidises the majority of aged care, the design of RACFs must meet this additional set of standards in order to achieve building certification and care provider accreditation to remain operational.

The 1999 Certification Assessment Instrument is used to ascertain the quality of the built environment through a visual assessment by a government-approved assessor for ongoing accreditation (Australian Dept. of Health and Ageing 2005; Hunter & Elkington 2005). Notably, the sections on safety, hazards, access, and security occupy 72 of the possible 100 total points. The only section that relates to enhancing quality of life is the section on privacy, which briefly describes the number beds per room and the configuration of bathrooms to reduce overlooking (Australian Dept. of Health and Ageing 2005).

Architects work within an onerous system that emphasises compliance with a set of documents to meet multiple bureaucratic procedures that are highly prescriptive with regard to risk minimisation, health, and security-based predominantly on the fear of falls and infection. There are significant sanctions for identified hazards or non-compliance with safety requirements (Australian Dept. of Health and Ageing 2005, p. 33) but in contrast, no incentive to provide a building that enhances lived experiences and well-being for RACF residents.

Paradoxically, the prioritisation of safety and risk management has been directly correlated with a measurable reduction in individual resident control and corresponding well-being (Popham & Orrell 2012). Thus, the building codes and guidelines are incongruent with the stated objective of government policy to meet increasing consumer expectations about lifestyle. Policy-makers have,

however, recognised that the coming generations of RACF residents have ‘seemingly higher expectations of being able to exercise greater control and personal choice in their lives as well as demanding high-quality service and facility provision’ (Productivity Commission 2011a, p. 54).

Furthermore, the BCA and certification standards do not take into account the changing demographics of RACFs described in Chapter 2. The BCA contains no reference to dementia, and the certification guidelines provide only a single link to an external document about designing for dementia: the Alzheimer’s Australia position paper for assisting ‘architects and builders who design and construct aged care accommodation’ (Australian Dept. of Health and Ageing 2005).

While not compulsory, standard design guidelines that supplement the regulatory requirements discussed above have been developed by the NSW, Queensland, and Victorian state governments (Hunter & Elkington 2005; Queensland Government 1999; Victorian Government Department of Health 2012; Victorian Government Department of Human Services 2000). These guidelines reflect a medical model of rehabilitative care and perpetuate the widely accepted and problematic ideologies of fostering independence and autonomy as discussed in Chapter 2. Reflected in this is that the design guidelines contain only minimal reference to designing for moderate dementia.

Although people are delaying admission into an RACF, until the final stages of life, the design guidelines, the BCA, and the certification standards do not include any consideration of RACFs as a setting for late-stage dementia, ageing, and dying-in-place, death, or for removal of bodies (Australian Dept. of Health and Ageing 2005; Hunter & Elkington 2005; Queensland Government 1999).

Irrespective of architects’ intentions and expressed aims by policy-makers to provide quality environments, design is driven by meeting compliance requirements, minimising upfront capital costs, and enacting current ideologies of clinical care (Buse et al. 2016; Macmillan 2006). This leads to design becoming focused on procedures and checklist, which is often at the expense of consideration of RACFs as therapeutic environments.

While for many people with dementia, the RACF is their final place of residence, it is also a place of work for the staff, the place that families visit, and a capital asset for the care organisation and shareholders (McDonald & Turner 2011). Each group has different and often conflicting needs adding to the complexity of the design process. Several authors argue however that RACFs are more often considered regarding task efficiency and providing physical care rather than consideration of residents’ lived experiences (Aggarwal et al. 2003; Moyle et al. 2013).

The influence of building design on well-being is often not well understood by the care staff and RACF management (Calkins 2009; Stillfried & Fleming 2013). Post Occupancy Evaluations (POEs) that may provide some insight into the resulting impacts on lived experiences of those that live, work, and visit are rarely commissioned. Further, current POE’s tend to focus on the ‘whats’ of buildings rather than how people experience spaces (Chalfont & Rodiek 2005).

There is little incentive to undertake POEs due to the cost as well as fear of criticism and the impact on the public image of the care organisation (Calkins 2009; Torrington 2007). There is also a limited appreciation of the value of POEs to inform design (Ulrich 2006), and in some cases, professional indemnity insurers preclude POEs to avoid potential liability by management, which could be construed from negative feedback (Calkins 2009).

The design of RACFs has increasingly become about maximising use of space and minimising capital and operational costs (McDonald & Turner 2011; McLean 2007). The trend for fewer aged

organisations and larger facilities described in Chapter 2 has led to the further standardisation of designs and larger multi-purpose spaces within the RACF to maximise resident supervision by fewer staff (Barnes 2006).

Together with the compliance driven and financial efficiency model of design, the scientific and technological focus of architecture is resulting in the rising homogenisation of buildings and spaces (Holl et al. 1994; Lefebvre 1991). Phenomenologists are highly critical of the dominance of objective knowledge applied to produce spaces that others must live in (Harries 1997; Pallasmaa 2006; Zumthor 2006a). The emphasis on 'production', efficiency, cost-effectiveness, and systemised construction and design generates buildings for people to occupy rather than '*dwel*' (Davidson & Milligan 2004; Milligan & Wiles 2010).

Social aspects of space, if considered, are intellectualised, with design focusing on the performance-based and material elements of built environments (Harries 1997). While lived spaces are experienced symbolically and emotionally, bounded spaces are conceived empirically and designed for functionality (Lefebvre 1991).

A further challenge to the notion of lived spaces is that buildings are created by a profession within a modern culture which privileges sight at the expense of the other senses (Markus & Cameron 2002; Pallasmaa 2006; Protevi 1998). Harries (1997, p. 26) proposes that as long as architectural theory and the conception of the built environment remains dominated by an aesthetic approach, the buildings and spaces produced can only result in a functional building 'with an added aesthetic component'.

Pallasmaa (2005, p. 17) believes that many aspects of the 'pathology' of contemporary architecture can be apprehended through an analysis of the hegemony of vision in modern society. The pathology Pallasmaa (2005) refers to relates to increasing experiences of alienation, detachment, loneliness, and isolation in our technological and visually dominant world. The overly simplified physical aspects of home within the RACF leading to distress, confusion, and alienation critiqued in Chapter 2 exemplify this argument.

The current issues driving design in Australia outlined above are expected to compound in the future due to an increased demand for RACF places, and changing demographics and community expectations. The lack of guidance for architects for designing for subjective lived experiences, or death and dying are important omissions given the increasing prevalence of residents with dementia and the core role of contemporary RACFs as places where people spend their final months of life.

### **3.4 'Best Practice' Design for Dementia**

A review of the academic literature reveals that there is little research in the Australian context and much of the research to date has been undertaken in the UK, USA, and Northern Europe. In particular, Sweden, Norway, Germany, and the Netherlands are leading the way in innovative approaches to aged care provision and environmental design for people with dementia (van Uden et al. 2013; Verbeek et al. 2012).

Although there is not an explicitly 'best practice' identified within the literature and likely that there is no single design solution, there is considerable interest in providing smaller, '*homelike*' environments for people with dementia (Ausserhofer et al. 2016; Ibrahim 2018; Verbeek et al. 2009). Models for small-scaled care homes include the Greenhouse in the USA, Domus in the UK, Group Living in Sweden, Cantou in France, and Small-scaled Living in the Netherlands (Coomans et al. 2011; De Rooij et al. 2011; Rabig et al. 2006; Verbeek et al. 2009). Generally, Domus and Cantou are

conceived as places to live until death, whereas dying-in-place in the other models is less defined (Coomans et al. 2011; Verbeek et al. 2009).



Figure 3.1 Domestic scaled resident kitchen and dining room. Björkens äldreböende Nursing Home, Järfälla, Sweden

While the design models referred to above vary in size and number of residents, they usually include a resident-accessible kitchen and attempt to exclude institutional features such as long corridors, nurses' stations, and medication trolleys (Coomans et al. 2011). The various models identified are not only a physical concept but are usually also entwined deeply with a social model of care (Verbeek et al. 2009; Verbeek et al. 2010).

Despite increasing acceptance of alternative small-scale models, there remain contradictory research findings including no link between size and neuropsychiatric symptoms (Bicket et al. 2010; de Rooij et al. 2012), and less social withdrawal in larger units (Ausserhofer et al. 2016; Zeisel et al. 2003).

Further, while there were fewer declines in activities of daily living (ADLs), higher satisfaction and emotional well-being in smaller units than in larger traditional homes, there was either no change or worse agitation and behavioural problems (Chaudhury et al. 2017; de Rooij et al. 2012).

Confounding research findings is that there is often several differences beyond physical size between smaller facilities and larger, general-care RACFs (de Rooij et al. 2012; Verbeek et al. 2010).

Differences may include higher staff to resident ratios, dementia specific staff training, and an emphasis on ordinary daily activities are more common in smaller than larger care facilities (Verbeek, 2010). Concepts for domestic-scaled environments for people with dementia vary internationally, and definitions are inconsistent (Verbeek et al. 2009). Definitions for 'small' can include aged care units from five up to 150 beds (Leon and Ory 1999 in Fleming & Bennett 2009a).

More recently developed but not yet widely spread, concepts of environments for people with dementia include a village-model exemplified by De Hogweyk (Abend & Paramaguru 2014) and Green Care Farms in the Netherlands (de Boer et al. 2017). Green Care Farms combine care with agricultural activities including gardening, animal care, and daily household chores (de Boer et al. 2017). De Hogweyk consists of domestic scaled-shared dwellings of 6-8 residents grouped by their previous 'lifestyle' preferences, as well including a café and other typical village amenities in a safe, enclosed space (Abend & Paramaguru 2014; Noone 2012). The focus of these models is for resident subjective well-being and providing as normal a life as possible (Coomans et al. 2011; de Boer et al. 2017). In both cases, the research has shown no change in clinical outcomes but definite improvements in quality of life compared to general long-term care facilities. In line with government policies, The Netherlands and Sweden have been increasing the number of small-scaled developments for people with dementia over the last 10-15 years (de Boer et al. 2017).

Australia, however, is generally lagging behind other countries in providing small-scale or alternative models beyond large RACFs (Ausserhofer et al. 2016), although there are a few village-type projects

in the conceptualisation stages. While the models discussed may inform this study, Australia has significant cultural, social, political, and funding structure differences and it is likely that the concepts may not be directly transferable to larger facilities.



Figure 3.2 Residents are engaging in 'normal activities' in a home environment: Overspaarne Nursing Home, Haarlem, Netherlands.

In addition to small-scaled models, principles of 'best practice' design can be inferred from the literature. Best practice includes designing spaces that support privacy, dignity, and familiar activities (Fleming et al. 2016; Lum et al. 2008), providing a choice of living spaces and encouraging social interaction (Calkins 2013) and rooms with a clearly identifiable purpose to minimise confusion (Calkins 2011; Chaudhury et al. 2013).

The Dementia Enabling Environment principles were developed in Australia based on the last thirty years of environmental research and aligned with recommendations by other leading environmental scholars including Chaudhury, Bawley, Calkins, and Zeisel (Fleming et al. 2013). There are ten evidence-based principles with considerable overlap including the need to consider the experience of building scale, unobtrusively ensuring safety and minimising risks, supporting orientation and way-finding, optimising and regulating stimulation, supporting residents' remaining capacities, and providing a sense of homeliness and meaningful activities, and opportunities for social engagement (Fleming et al. 2013). While these principles relate to people with mid-stage dementia, there is likely to be both differences as well as some overlap with the needs of people with late-stage dementia.

Legibility is an integral part of the human scale of RACFs that is important for providing familiarity and maximising orientation for people with dementia but often lacking (Chaudhury et al. 2013; Fleming et al. 2016). Chaudhury et al. (2017) and Fleming et al. (2016) argue that buildings need to bring opportunity for delight as well as support them to understand where they are.

Colours and edge contrast are highly recommended as many people with dementia have depth perception issues (Calkins 2013). Meaningful cues within the physical environment need to be provided to support their navigating ability as well as to afford 'purposeful walking' rather than aimless and potentially more problematic wandering (Fancey et al. 2012; Fleming & Purandare 2010). While many of these principles such as way-finding relate to best practice for people with mid-stage dementia, it is likely there will be some similarities for those with late-stage dementia.



Figure 3.3 Contrasting door and wall colour for visual clarity. Plejecentret Lindehaven Nursing Home, Ballerup, Denmark

Further to supportive and best practice environments for people with dementia, is that independent access to gardens (Zeisel 2013) and views of nature (Chalfont 2007; Cioffi et al. 2007) have also been found to provide significant therapeutic value. The well-being of people with dementia has been found to continue to be strongly influenced by a connection with the natural environment and by gardening which affords the opportunity to leave a legacy, find a sense of meaning, interact with others, and enjoy physical exercise (Austin et al. 2006; Wright & Wadsworth 2014). Gardening is said by Wang and MacMillan (2013), to facilitate a mind-body connection, and Chalfont (2006) describes phenomenological-based benefits of nature-based activities for providing multi-sensory experiences and a connection with the cycles of nature and an ongoing subjective relationship to the natural world.

The majority of environmental research, however, is empirical research by psychologists, gerontologists, and nurses rather than architects and rarely about the person-environment interaction (Sloane et al. 2008) or how people use, feel, and interpret spaces (Chalfont & Rodiek 2005). While their contributions to knowledge are significant, architects are likely to consider the environment from a different perspective but have done minimal academic research.

Notwithstanding the valuable research contributions made by architect researchers including van Steen Winkel and colleagues, Brawley, and Calkins, a further issue related to the limited architectural research is that there is considerable evidence that design research for people with dementia is not translating into practice (Brawley 2005; Calkins 2011). Proposed reasons include a lack of confidence about predicting the results of environmental research for people with dementia, limitations on innovation due to compliance and fiscal drivers discussed in Chapter 3, and a lack of awareness of, or access to, the environmental research by practising architects (Fleming et al. 2012; Van Hoof et al. 2014).

Calkins (2009) posits that despite the poor uptake of dementia-specific environmental research, design happens anyway, concluding that the design of care settings is at times, based on conjecture, unsubstantiated and anecdotal information. Both architects and care organisation managers have been found to make assumptions based on personal experience about how the general population perceive and use buildings, which may be different for people with dementia (Calkins 2009, p. 153; Day et al. 2000).



In an attempt to improve environmental design for people with dementia, a plethora of 'tools' to assess aged care buildings have been developed (Fleming 2009; Fleming et al. 2013; Lewis et al. 2010; Slaughter et al. 2006). Use of the tools is not a regulatory requirement for RACF accreditation and certification but provides a voluntary evaluation of both existing environments and new designs of RACFs (Bennet et al., 2013). Their use may also be considered 'best practice'.

Building assessment and auditing tools include the Multiphasic Environmental Assessment Tool (MEAP) (Moos & Lemke 1984 in Fleming & Bennett 2009a), Professional Environmental Assessment Protocol (PEAP) (Lawton et al. 2000), and Sheffield Care Environment Assessment Matrix (SCEAM) (Parker et al. 2004). The Environmental Assessment Tool (EAT) is evidence-based and developed in Australia. It is founded on the Enabling Environment Principles discussed above and is the tool primarily used in Australia (Bennet & Fleming 2013b; Fleming 2011).

Audits are generally a walk-through, and sight-based assessment focused on building size, residents' requirements to orient themselves and move independently within the RACF, resident safety and security, and levels of stimuli within the environment (Bennet & Fleming 2013b). There is no scope within the tools to include the perspectives of people with dementia, family or staff, or additional subjective evaluations by the assessor. An additional limitation is that evaluating buildings by a checklist does not assess the difference between the intended and actual use of the building (Torrington 2007), or the influence of the environment on lived experiences.

The tools are derived from over twenty years of environmental research (Bennet & Fleming 2013a), both the research and resulting tools are almost exclusively empirical measures generally for residents with early to mid-stage dementia (Popham & Orrell 2012). Although the tools provide valuable evaluation methods, there is a need for a more comprehensive understanding of subjective responses to influences of the built environment for people with dementia.

### **3.5 A brief review of environmental research literature**

Research to date has been largely empirical, focusing on managing behaviours and medical issues. There is little research about people in the later stages of dementia residing in the RACF (Calkins 2011; Fleming et al. 2017; Fleming et al. 2015). We cannot assume the needs of people in the final stages of dementia characterised by immobility and lengthy bed stays are the same as those in the mid stages, but little remains known about their environmental needs (Calkins 2005). It is likely that the objective knowledge to date has little relationship to subjective lived experiences in the final stages of life.

Evidence-based research, however, is often held up as the 'gold standard'. The focus on objectivity provides useful insights into functional and clinical performance aspects of the physical building but gives little understanding of how and why people use the spaces the way they do (Chalfont & Rodiek 2005). While there has been growing interest in the influence of the built environment on well-being and spaces for healing in general healthcare settings (Sternberg 2010; Ulrich et al. 2010), there has been significantly less research specific to RACFs in this field.

Further, there are surprisingly few studies about the complex inter-relationship between people, the environment and well-being, although there has been awareness of the concept since at least the times of Florence Nightingale (Chaudhury et al. 2017). Embedded in a modernist architecture guide, The Athens Charter is a similar idea, and several modernist architects, notably Alvar Aalto and Richard Neutra were explicit about the relationship between architecture, nature, and health and the therapeutic influence of quality design on well-being (Sternberg 2010, p. 5). Aalto's 1930's highly regarded Paimio Tuberculosis Sanatorium (1929-33) was an exemplar of designing for the individual's

access to sunlight, fresh air, views of nature, and social opportunities to encourage healing, and remains in use as a hospital at present (Weston 1995).

There is more recent scientific evidence that the built environment contributes to well-being (Sternberg 2010). A longitudinal study found that people with access or a view of nature were discharged from hospital and required less pain medication than those that did not (Sternberg 2010; Ulrich 2006). Regardless of findings, practice lags behind theory regarding designing healthcare buildings as therapeutic spaces (Ulrich et al. 2010).

Despite the complexity of RACF environments, much of the existing research has used deductive, hypothesis-testing designs to describe and correlate individual environmental characteristics to specific and measurable aspects of health and behaviours (Brawley 2005). Many of the studies are quasi-experimental or attempt to reduce the environment to single quantifiable factors of how people with dementia relate to the environment at a cognitive level (Algase et al. 2007, p. 266).

These approaches overlook the complexity of how people relate to the environment at an emotional level, which is not adequately understood due to the rudimentary stage of our theoretical and methodological development (Algase et al. 2007, p. 266). Research using qualitative, in-depth approaches that inter-connect people and the environment are rare (Edvardsson 2005; Edvardsson et al. 2005).

Further, the majority of environmental research to date about people in the RACF environment focusses on the needs of people with dementia. While there is a consensus that people with dementia need the support of others to maintain a connection to self (Moyle et al. 2011), and that their primary source of well-being is their relationships with family (Ettema et al. 2005; Merz & Huxhold 2010), little is known about the needs of the family within an RACF environment.

Research in other healthcare settings has identified that environmental factors can positively affect family relationships. Carpeted floors and provision of a 'family zone' in ICU rooms in Young-Seon and Bosch' study (2013), and private discussion areas and designated family spaces in hospitals supported families to interact more, stay longer, visit more frequently and assist to care for their loved one (Ulrich 2006; Ulrich et al. 2010). Less is understood about how to support families to feel more welcome in RACFs, which is an important omission as many families continue to spend considerable time in the RACF especially during the final stages of their relative's life.

Chapters 2 and 3 demonstrated that there is little evidence that the design of RACFs has been considered regarding lived experiences or as a setting for late-stage dementia and dying (Davis et al. 2009; Hennings et al. 2010; Rigby et al. 2010). However, there have been significant contributions to understanding and consensus in research about designing environments for people with early to mid-stage dementia over the last twenty years (Fleming et al. 2016). As a result, the focus has been on strategies to enhance way-finding, the provision of unobtrusive safety measures to support independence and ways to reduce issues such as inter-resident aggression, agitation, and absconding, but there is less known about the effect of the environment on lived experiences.

In Heideggerian research, both spaces and place should be understood primarily according to the human experience of building and '*dwelling*', not through logic or science (Dahlstrom 2010; Hellberg et al. 2011). Our lived experience of space and place in the context of the built environment is understood through our emotional responses and multi-sensory experiences, primarily comprehended through use and experience (Chaudhury & Cooke 2014). Space that is conceived as a series of dimensions and objective measurables is overly abstracted. These spaces often lack a connection with human experiences (Lefebvre 1991). The phenomenological appreciation, which

emphasises the ways people experience place, offers a richer way to describe the world than mathematical abstraction and visual descriptions (Heidegger & Hofstadter 1971, pp. 155-156).

Van Manen (1990) conceptualised lived space as 'felt' space related to the feeling of 'being in place' rather than simply an objectified physical space. Heidegger proposed that we make sense of things by experiencing them in context (Im & Meleis 1999; Sharr 2007; Tuohy et al. 2013). Both Gadamer (2004) and Malpas (2012) conclude that we are only judging and assessing buildings visually unless we spend enough time in them to understand the impact on well-being and lived experiences of those that inhabit those spaces. However, the majority of research concerning RACF environments to date has mainly been objective and deductive, rather than immersive and comprehensive or about subjective lived experiences.

While there is a growing interest in RACF design regarding place-making and the influence of a sense of place on subjective lived experiences, further research is required particularly regarding how this might affect design for people with late-stage dementia. Andrews (2003; 2008) argues the concept of place is poorly understood in nursing practices and few studies assess the impact of place on lived experiences.

### **3.6 Discussion**

Chapters 2 and 3 have demonstrated several limitations in the current conceptualisation of RACFs as spaces to support subjective lived experiences or as places in which many people with late-stage dementia will die. These chapters began to articulate some of the issues in the provision and design of RACFs that have the potential to affect the everyday lifeworld of people with dementia, their families, and staff.

In sum, limited attention has been given to how the design of the RACF built environment can support lived experiences nor to understanding the lived experiences of residents dying with dementia, or the experiences of their families and staff. Research generally into the end of life experiences of dementia from resident, family and staff perspectives is limited (Hennings et al. 2010). Their views are rarely sought in research or design processes.

Scholars argue that there is limited research from the perspective of people with dementia (Dewing 2007; Goodman et al. 2011). As a result, people dying with dementia represent the most under-researched people in our community, and we have limited knowledge of their lived experience or environmental needs (Dewing 2007; Nolan et al. 2006).

People with dementia have been excluded from research for several reasons including perceived communication issues, meeting project timeframes, and complexities in gaining ethics approval. The salient points here, however, are that without direct inclusion in research, our understanding of the well-being and lived experiences of people with dementia are only partial (Dewing 2002, 2007; Kitwood 1997).

It is also likely that people with late-stage dementia have been excluded from research because some within the research and care community believe that they have limited awareness of their surroundings, and diminished ability to communicate their feelings. However, both Dewing (2007) and (Sabat 2005) identified that an ability to recall events and experiences including emotional affect remains present well into advanced dementia. The work of these scholars, as well as that of Goodman et al. (2011) and McKeown et al. (2010), inspired the need to include people with dementia directly in this study and the research approach.

Factual and interpretative debt is also owed to Nolan. His work about the relationship-centred care that is situated and where everybody in the care relationship is equally valued provided a conceptual shift in my thinking about how humans experience the world, and how this might influence my research approach. Nolan's (2004; 2002) reciprocal care model informed the philosophy of the collaborative, inclusive research methodology employed in this study.

This study has also benefited from the work of Fleming, McGann, and Lawton. With over 30 years of dementia-specific research in Australia, the influence of Fleming in this project is undeniable and provides a foundation for thinking about how the built environment influences well-being for people with dementia, and the potential for the environment as a therapeutic resource. McGann's exploration of the relationship between what is perceived and conceived and the influence on lived experiences in hospice spaces initially inspired the need for a phenomenological approach in this study. Lawton's advocacy of multiple, eclectic theories and multi-faceted, comprehensive research involving several methods and theories, as well as including multiple participant groups informed my research design, which is detailed in Chapter 4.

The background chapters have demonstrated that despite the tendency for increasing numbers of people to delay admission to aged care until they are very frail, many of whom have a diagnosis of dementia, the focus of care and design remains on a restorative medical model. The resulting environments are clinical in feel and appearance as design is driven by the medical model, and by compliance and risk management requirements.

While notions of '*RACF as home*' are included in some RACF design guidelines and in research as an apparent solution to providing a supportive environment, the concept remains loosely framed and applied in practice. Focus on the physical aspects of the family home is, however, a static notion, and when a resident in an RACF calls for home as identified by Varley (2008), there is little to suggest that the current framing of '*RACF as home*' is providing for their well-being.

The focus on '*RACF as home*' and the issues discussed above also suggests that we do not know how an RACF should feel and that this may vary between individuals. This points to the need for a phenomenological approach to deepen understandings of how residents, family and staff experience and make meaning of the environment. An inherently collaborative and interpretive approach was anticipated by the nature of the study and the potential communication issues of the participants, leading to the selection of a hermeneutic phenomenological approach. The research philosophy and design are described in detail in Chapter 4.

## **Chapter 4: BEING-IN-THE-WORLD-OF-BEING-IN-AGED-CARE: A METHODOLOGICAL APPROACH**

Chapters 2 and 3 investigated current theories, design practices, and shortcomings in the provision of RACFs for supporting lived experiences of people with dementia, and their families and staff. Chapter 3 concluded by identifying the need for an immersive study and collaborative approach that engages people with dementia as research participants to develop a comprehensive understanding of being-in-the-world-of-aged-care.

Chapter 4 introduces the research philosophy of hermeneutic phenomenology, outlines central concepts, terminologies, and qualities of a hermeneutic phenomenological approach and methodology, and on that basis describes the research design. The complexity of the issues outlined in Chapters 2 and 3, as well as the diminished cognitive and communication capacity of people with dementia, calls for a careful, innovative, and sensitive research approach. To this end, the research was designed to be naturalistic, multi-faceted, and with real-time feedback to collaboratively develop interpretations of lived experiences of being-in-the-world-of-aged-care. An essential quality of my design approach was my immersion in the wing of an RACF, working voluntarily in addition to my research which helped to establish relationships that helped to enable the residents to participate.

Section 4.1 argues the selection of a hermeneutic phenomenological approach. The fundamental philosophical concepts of the methodology, and how authenticity and research rigour is achieved is also explained. Section 4.2 discusses the ethical issues of involving people with dementia in research, and the design of recruitment and consent procedures to address these issues. The research methods and reporting of how research and interpretive processes were carried out are described in Section 4.3. My conversation partners, myself as a research participant and the presentation techniques used to give voice to the participants are introduced in Section 4.4.

### **4.1 Engaging in the-world-of-being-in-aged-care**

#### **4.1.1 A rationale for a hermeneutic phenomenological approach**

From the field of qualitative methods, the selection of a hermeneutic phenomenological philosophical approach was anticipated by the focus on lived experiences, which requires attention to language, multiple voices, situatedness, reflexivity, and acknowledgement of the value-laden nature of research (Dahlstrom 2010; Finlay 2009; Healey-Ogden & Austin 2011).

The underlying epistemological foundation of hermeneutic phenomenology is about bringing to light through language the meanings of lived experiences acquired (Moustakas 1994; Newman et al. 2010). 'It seems rather, to be generally characteristic of the emergence of the hermeneutic problem, that something distant has to be brought close, a certain strangeness overcome, and a bridge built' (Gadamer et al. 2004, p. 22). In other words, we attempt to understand everyday lived experiences that may not otherwise be reflected upon or unveiled.

As will become further apparent in Chapters 5, 6, and 7, there are few places more sequestered from the community than that of an RACF. This is a result of the stigma commonly associated with institutionalised aged care and rare visits or time spent in RACFs by the majority of the population. The removal of people with dementia from the community renders their lives and lived experiences hidden. A hermeneutic phenomenological approach seeks to form a link between the readers' lifeworld and the lifeworld of people living and dying with dementia, and their family and staff.

Further reasoning for my research approach is the appropriateness when involving people with dementia in research as the hermeneutic phenomenological philosophy is aligned with Kitwood's

notion that all 'actions and utterances are assumed to be meaningful, and an attempt is made to understand them in their context' (Kitwood 1997, p. 27).

Hermeneutic phenomenology promotes even demands, an attention to language and symbolism in the use of language, and an attitude of reflexivity. This can include body language, pluralism, propositional theory, and awareness of the value-laden nature of knowledge and stories, in all their complexity and contradictions (Heidegger 1962, p. 59; Risser 2015). The aim is to transform these communications of lived experiences into a text that is both a reflexive and reflective expression of meaningful essences, ideally allowing the reader to reflect on their situatedness, and that of similar settings (Van Manen 1990).

The nature of the study of lived experiences required an inherently collaborative relationship between the researcher and the participants. A theoretical framework and research design that valued diversity and the intrinsic worth of all persons, as well as addressed the complexities of each person's lived experiences and subjective meaning-making of the place in which they found themselves was essential. Accordingly, in keeping with the notion of valuing all persons in a reciprocal care relationship discussed in Chapter 3, hermeneutic phenomenology was the most intuitive and logical choice for this study as it also values and situates all persons in the research relationship.

People and place are a complex multi-dimensional construct, and unless understood from multiple perspectives, the knowledge derived is likely to remain incomplete (Armstrong 2003; Hellberg et al. 2011). The starting point of my fieldwork is the belief that the RACF world is seen, experienced, and made meaning of by each person, in their own way, and that building design ought to be guided by an understanding of the subjective lived experience of the building users, that is, people with dementia, and their family and staff.

Thus, while many research methods involve a 'commencement' with clearly articulated research questions, hermeneutic phenomenology does not (Smythe et al. 2008). The research approach adopted here is an exploration through reflexive research, reflection, and interpretation that is guided by the participants and situatedness (Rubin & Rubin 2005; Smythe et al. 2008). Hermeneutic phenomenology is a practical philosophy that does not attempt to answer specific problems, but rather develops in-depth understandings and seeks patterns of meanings (Kidder 2013). It is an inductive approach that is developed progressively, welcoming questions, and theories that emerge throughout the research (Dahlberg 2006). Thus, 'the lifeworld, the world of lived experience is both the source and the object of phenomenological research' (Van Manen 1990, p. 38).

The hermeneutic phenomenological approach creates a conversational relationship while being mindful that the language of lived experiences is of a discursive nature. This requires the reflexive researcher to look for the subtle social undertones of meaning-making in the individual account, asking how relating events, stories, and assumptions might have been produced through discourse, culture and social practices (Kamler & Thomson 2006; Van Manen 1990).

The challenge of hermeneutic phenomenology is to use innovative and appropriate devices tailored to be sensitive to the needs of the participants and communicated in a way that is authentic, honouring the participants and their stories, and that is relevant and evocative for the reader (Dahlstrom 2010; Saevi 2013). Research methods employed are detailed in Section 4.3.

In contrast to other qualitative research methods where the researcher is required to remain removed from the subject, hermeneutic phenomenology uses 'close observation' and 'language-based methods' and tries to break through the observational research distance to enter the lifeworld

of the persons studied (Van Manen 1990). Malpas (2015) and Hellberg et al. (2011) propose that the most effective way to enter a person's world is to participate in it, not by simplistically just 'being-in-the-world-of-aged-care'. They advocate that retaining hermeneutic alertness to situations allows us to constantly step back and reflect on the meaning of those situations, and to observe the self in the research setting (Hellberg et al. 2011; Malpas & Gander 2015). Thus, this hermeneutic phenomenological study employed an approach that required simultaneous positioning as researcher and participant, maintaining reflexivity while immersed in the lifeworld explored.

#### **4.1.2 A philosophical approach to exploring the world-of-being-in-aged-care**

Phenomenology and hermeneutic phenomenology are frequently employed interchangeably in the literature (Lavery 2003). There are ontological, epistemological, and methodological differences between the two approaches although hermeneutic phenomenology evolved from phenomenology (Dowling & Cooney 2012; Herrmann & Maly 2013). Husserl was generally considered the founder of phenomenology, which he envisaged as a philosophical approach that rejected the rational bias that had dominated thought since Plato's time to understand qualitative experiences (Dowling & Cooney 2012; Herrmann & Maly 2013).

A key criticism of Husserl's phenomenology was that it attempted to understand lived experiences scientifically, necessitating the researcher to bracket and set-aside their subjectivity, presuppositions, and personal biases (Gadamer et al. 2004; Kjällman-Alm et al. 2013). It was Husserl's student, Martin Heidegger who developed hermeneutic phenomenology in response to his criticism of Husserl's positivist approach in phenomenology, which attempted to understand subjective experiences objectively (Lavery 2003). Heidegger believed it was an unrealistic expectation of researchers to extract or suspend themselves from the lifeworld for research objectivity (Gadamer et al. 2004). Somewhat logically and realistically, Heidegger argued that both the researcher and those in the research can only view the world from their perspective and that this point of view is temporal (Hellberg et al. 2011; Kjällman-Alm et al. 2013). It was Heideggerian thinking rather than that of Husserl, which underpins the methodology I adopted.

The goal of hermeneutic phenomenology is to capture people's meaning-making of events and their emotional relationship to the essence of a place from the perspective of the person experiencing the lifeworld (Tan et al. 2005). Heidegger's hermeneutic phenomenology combines key concepts of phenomenology with hermeneutics, a language and text-based analysis that embeds and situates the participants in the research itself as well as in the interpretive cycle exploring shared interpretations and equally valuing everyone in the research relationship (Kafle 2011).

A concise definition of hermeneutic phenomenology is that it is an approach rather than a method. It aims to collaboratively develop understandings with the participants of concealed meanings and essences of their experiences situated within a lived world (Starks & Trinidad 2007). Underpinned by the work of Heidegger and Gadamer, hermeneutic phenomenology follows a more interpretive and existential philosophical direction than phenomenology (Dowling & Cooney 2012; Finlay 2009). However, rather than simply reporting another person's experiences, we need to see beyond the ordinary everyday meaning of life to 'see the larger meanings in being, to uncover hidden meaning and move beyond description to the interpretation of lifeworlds' (Dowling & Cooney 2012, p. 24).

#### **4.1.3 A reflective and reflexive approach**

While researchers are of course, always required to design research that is congruent with the philosophical underpinnings of their chosen methodology, there is no prescription for conducting hermeneutic phenomenological research (Kvale 1996; Newman et al. 2010). While the lack of a

methodological guide is itself a challenging notion, an extensive review of the literature revealed a variety of approaches taken rendered the issue of research design more complicated. Some were more credible and closely aligned with the hermeneutic phenomenological philosophy than others, while several were positivist in approach.

The fundamental requirement was for an approach that allowed a gathering of people's stories of lived experiences. This suggested a predominantly narrative-based approach to be converted into a hermeneutic text for theorising, interpreting, and conveying meanings (Boden & Eatough 2014; Kafle 2011; Newman et al. 2010). The practical nature of being-in-the-world-of-aged-care demanded an inquiry that extended beyond philosophising or abstract theorising, to one that employed writing to focus 'our reflective awareness on the practice of living' (Van Manen 1990, p. 127). In this way, theorising became integrated with the practice of writing not only with researcher reflections and interpretations but also in the conducting of the research itself.

In hermeneutic phenomenology, writing is not merely the tool used to provide the final product. Instead, it is considered that to write is to think, to reflect, and to understand. Writing is used simultaneously to distance us from the observed and shared lived experiences yet engage and draw us 'closer to lifeworld and discovery of the existential structures of experience' being conveyed (Van Manen 1990, p. 127). The goal is to bring us closer to understanding the world that we have entered: the-world-of-being-in-aged-care.

Writing becomes part of the researcher's immersion within the lived experiences, as both mediators of experience and a phenomenon mediated by experience (Van Manen 1990). While language is itself abstractive, writing consolidates thought into text and at the same time, it subjectifies our understanding of something that truly engages us (Saevi 2013; Shumack 2010).

When we write, we are not writing about what happened; rather we provide a representation of events, a description that is already an interpretation, constructed by language, the historical circumstances, and the specific environment (Gadamer et al. 2004; Kamler & Thomson 2006). This process of writing is understood as an interpretation and value-laden (Lindseth & Norberg 2004). As Gadamer et al. (2004, p. 68) theorise 'when we interpret the meaning of something, we interpret an interpretation' selectively paying attention to some things, and less to others.

Kamler and Thomson (2006, p. 66) identify that 'reflexivity involves continual self-interrogation' as a means to develop personal awareness of our interpretative processes. To this end, I maintained a reflective journal throughout the study. The journal entries were written in an unrestrained, free-flowing manner capturing my inner responses, questioning, and personal processes. Initially, reflections focussed on theoretical perceptions of being-in-the-world-of-aged-care. Later journal entries contemplated emotional responses to experiences and events in the research setting and clarified preliminary interpretations and understandings of participant stories. At times, reflections were evaluative, even speculative, while at other times they were intuitive and conceptual.

These reflections were particularly useful to inform interpretations and as a record of progression of my thinking. This reflective process created a context of personal accountability allowing refinement of research processes and understandings developed progressively rather than drawing one final overarching conclusion at the completion of fieldwork.

In addition, the field texts were carefully constructed to provide a transparent audit trail in keeping with the notion of rigour and validity in qualitative research (Booth et al. 2008; Kamler & Thomson 2006). Reflections and observations provided documented evidence in readiness for potential questions about knowledge claims, and how meanings were generated and research decisions made.



#### 4.1.4 Authenticity, rigour, and engaging the reader

Issues of rigour remain debatable, and the criteria for judging the quality of a qualitative inquiry is not precisely definable due to the complex and evolving nature of qualitative research. Qualitative researchers demonstrate rigour through research crafting characterised by a continual and transparent process of review, questioning, reflection, and interpretation used to corroborate meanings, and by showing rigour through integrity and competence (Kamler & Thomson 2006; Kvale 1996; Rugg & Petre 2010). The overarching processes in hermeneutic phenomenology for ensuring rigour are hermeneutic looping described in further detail below and demonstrating authenticity through the crafting of the text.

The burden of responsibility for evoking trustworthiness lies with the researcher and the text they produce (Evans et al. 2011; Kvale 1996). This study addresses trustworthiness by providing rich and thick portrayals of behaviours and interactions between participants, lengthy engagement with the participants in the research setting, insightful and accurate observations, and completeness of explanations (Kamler & Thomson 2006).

Richly descriptive writing contributes to the authenticity of the text because it is the detail and not the general that moves or touches the reader (Creswell & Creswell 2013; Wilson 2014). Characters are delineated, and their lifeworld stories told so that the participants are deeply embedded in time and place (Gadamer et al. 2004; McGovern 2017), which is more likely to make sense and engage the reader. Hermeneutic phenomenological studies such as this one is often real but also need to feel 'real' and 'alive', encouraging the reader to enter the world of the research setting (Richardson 1994 cited in Creswell & Creswell 2013, p. 21).

Hermeneutic phenomenology employs 'rich, descriptive language' seeking to engage the reader and encourage them to think about the experiences being conveyed (Kafle 2011, p. 191). The persuasiveness of the text indicates further proof of rigour and trustworthiness, and the evoking of the readers' emotional response is considered confirmation of rigour and authenticity (Doyle 2012). 'Thick' texts constructed in this study were used to aid both my understanding and interpretations of the complexity of the aged care context and to convey the experiences of being-in-the-world-of-aged-care to the reader for a multi-disciplined academic readership. I do not intend that my world-view will become that of the reader, but that the author will invoke situatedness that allows the reader to develop a sense of the context and the meanings revealed about lived experiences.

In keeping with a hermeneutic phenomenological approach, engaging with place was essential and enabled me to incorporate my own subjective experiences to persuade the reader that my emplaced observations were genuine. Similarly, a goal of this thesis is to engage with the reader's compassion, evoking emotional responses, and contextualism that provides an opportunity to identify with the participants' lived experiences. Ideally, the reader of the stories in the following chapters is inspired to reflect upon and to deepen their current understandings and transfer meanings or make comparisons with other settings that they are familiar with (Creswell & Creswell 2013; Denzin & Lincoln 2011; McCracken 1988).

Engaging the trust of the reader can be challenging. Several qualitative researchers recommend adopting a reflexive stance that addresses the issues of trustworthiness by engaging openly with the subjectivity of the researcher (Haraway 1988; Im & Meleis 1999). Reflexivity, where researchers engage in explicit, self-aware analysis, goes some way towards establishing believability and reducing the risk of writing self-indulgently in a way that focusses on the researcher (Doyle 2012).

To this end, I regularly engaged with other academics, peers, and my supervisors about the text and reflections, and continued to engage with the academic literature as a check on my reflexivity and interpretations. On revisiting interpretations and presenting early drafts of the participant stories, I realised that I had at times, 'diluted' the emotional intensity of both my responses and the original stories, particularly participants' related experiences of anxiety, fear, and grief. My tendency for this attenuation was due in part to my inexperience at evocative writing, my Australian culture which tends to downplay 'problems', and that I sometimes unwittingly assumed the role of objective researcher. This tendency reduced over time as I developed awareness of my predisposition, and my research and writing skills improved.

Reflecting was instrumental in maintaining reflexivity and as a result, I started to include more direct participant quotes, their emotional responses, and a more expressive representation of research events. I also allowed my positioning to be more revealed and was more candid in expressing my sentiments and interpretations, including the less favourable evaluations and 'truths'.

#### **4.1.5 A hermeneutic phenomenological approach to 'truth'.**

Hermeneutic phenomenology assumes that there is not one definitive explanation, absolute truth, or overarching theme for the phenomena studied, but that there is an acceptance of numerous truths (Holl et al. 1994). The truth or facts of experience are considered an abstract concept and our understanding personal, subjective, and already interpretive as soon as it is experienced, remembered or conveyed by language (Starks & Trinidad 2007).

There is no single theme, meaning, or perspective sought rather, a valuing and uncovering of multiple perspectives, alternate interpretations, and endless meanings (Creswell & Creswell 2013; Smythe et al. 2008). Hermeneutic phenomenology differs from most other research methods in that it attempts to gain insightful descriptions of the way we experience the world pre-reflectively (Van Manen 1990, p. 9). We are not trying to explain or control a person's lifeworld; instead, we aim to bring it to closer ourselves and to the reader to understand it.

The goal of hermeneutic phenomenology is not to develop knowledge by constructing or describing 'truth', but to seek to understand the meanings and subjective perspectives of the stories shared (Lindseth & Norberg 2004; Smythe et al. 2008). Lived experiences are not reported or described, rather a more interactive and reflexive process that acknowledges the role of the researcher's foreknowledge and perceptions of the experiences are collaboratively developed with the research participants (Doyle 2012).

Thus, naturalist studies are frequently criticised for being unscientific, failing to 'adhere to canons of reliability and validity in the traditional sense', and are perceived rather as a series of anecdotes, personal impressions, and social conversations (Creswell & Creswell 2013, p. 202; Denzin & Lincoln 2011). Positivists, in particular, argue that their knowledge is politically and socially neutral and that employing rigid procedures to measure 'truth' independent of human biases and subjectivity, provides readily demonstrable credibility and objectivity believed to be lacking in qualitative research (Denzin & Lincoln 2003; Kvale 1996).

A situated research approach challenges the traditional scientific notion of objectivity and creating distance between subject and object, and the distance between the researcher and the researched (Dahlstrom 2010). A situated study is in part, my response to the limitations of empirical research critiqued in Chapter 3. Further, according to Heidegger, it is impossible to understand lived experiences by being detached and why hermeneutic phenomenology is often characterised by a deep immersion of the researcher (Wilson 2014). Thus, it was essential that I found a way to

immerse myself in the world-of-being-in-aged-care, which I believed potentially best achieved through a single case study and by engaging simultaneously as both a participant working voluntarily and researcher.

We do research hermeneutic phenomenology in a way that resonates, is congruent and ‘feels like a good fit’ and make no claim that we are producing objectified truths or answers to questions (Smythe et al. 2008, p. 3). Further, scientific researchers contend that qualitative notions of ‘authenticity’, ‘trustworthiness’, and ‘dependability’ are an internal rather than a more readily recognisable external validation with measurable markers (Creswell & Creswell 2013, p. 202; Roberts 2013). In their determination to demonstrate rigour, many qualitative researchers adopt positivist-based paradigms, triangulating data, developing behavioural measures, and deducting themes and counting responses (Dale et al. 2012; Sharr 2007). The risk, however, in qualitative approaches that are more objective is that rich subtleties and unusual cases can be overlooked (Jahnke 2012; Pringle et al. 2011).

Thematic software such as NVIVO provides a comparatively empirical interpretation of qualitative information aiming to distance the researcher from the data (Van Manen 1990). As such, the use of software to facilitate analysis is not considered appropriate in hermeneutic phenomenology (Malpas & Gander 2015; Van Manen 1990).

The notion of theme used in various human science disciplines is often understood to be unambiguous and a relatively mechanical application of frequency (Kidder 2013; Van Manen 1990). In hermeneutic phenomenology, ‘formulating a thematic understanding is not a rule-bound process but a free act of ‘seeing’ meaning’ (Smythe et al. 2008, p. 5). Phenomenological themes may be understood as ‘structures of experience’ so that when we analyse a phenomenon, we are trying to determine experiential patterns that make up experiences (Van Manen 1990). Conventional coding processes adopted by other qualitative methodologies, which segment, thematise, and categorise data, are incongruous and potentially limiting in hermeneutic phenomenology (Smythe et al. 2008). Accounts of subjective lived experiences must retain their situatedness, individual subtleties, and quirks that are potentially lost in categorising processes.

Consequently, hermeneutic phenomenology is not a ‘tidy’ or systematic approach to interpretation. It is at times uncomfortable, a grasping of understanding where phenomenological themes are understood as clusters of meanings and essences with the potential for multiple interpretations (Håkanson & Öhlén 2016; Van Manen 1990). Hermeneutic phenomenological researchers do not count, deduce, or classify data; rather an inductive, reflexive, and reflective process is adopted (Malpas & Gander 2015). Hermeneutic phenomenology is a search for patterns, narrative threads, meaningful statements, or evocative fragments, tensions and inconsistencies, fundamental meanings and essences (Smythe et al. 2008).

Hermeneutic phenomenologists accept all stories about lived experiences as authentic and equally valid. The ability to ‘touch minds’ determines the extent of researcher understanding (Djivire et al. 2012). Phenomenologists acknowledge the ‘possible’ rather than attempting to prove the ‘actual’, exploring multiple meanings that include many voices and perspectives to create persuasive texts, and a ‘crystallising’ of understandings (Dale et al. 2012; Markula et al. 2001; Sarvimäki 2006). Instead of reducing gathered information into averages, hermeneutic phenomenology embraces outliers and differences as an essential aspect of the authentication process (Sarvimäki 2006).

Rather than ordering, sanitising, or attempting to simplify our research, hermeneutic researchers retain, even celebrate the stories that represent not only the differences but also the inconsistencies and incoherencies (Creswell 2009; Creswell & Plano Clark 2011, p. 15). A fundamental assumption of

hermeneutic phenomenology is that we are always engaged in our world and confronted with complexity and contradiction (Finlay 2009). Accepting the close interweaving of language and our lifeworld is also an acceptance that the RACF world will be seen and interpreted differently by each person (Wilson 2014). While managing multiple meanings can be challenging, hermeneutic phenomenologists have the tools described below to support interpretations.

#### **4.1.6 Hermeneutic looping and foreknowledge**

Central to a hermeneutic phenomenological approach is the hermeneutic loop, which is a device that provides a means of checking research rigour as well as a key interpretive mechanism (Dahlstrom 2010). Looping is an interpretive process where interpretations are 'looped' to participants, peers, and the literature for further re-interpretation (Creswell & Creswell 2013; Dahlstrom 2010). The researcher uses methods that generate 'thick' or 'rich' texts, which are then continually reflected on, interpreted, re-interpreted and 'looped' back to the research participants for further interpretation, and then re-interpretation (Dahlberg 2006).

Research rigour discussed in Section 4.1.4 is provided through a continuous exchange of reflective, critical reasoning and interpretation of the hermeneutic text through the looping process. It is referred to as a 'loop' as the process represents a potentially endless cycling of understanding and interpretation, allowing meaningful engagement with the experience that might expand our horizons and uncover a new perspective or previously unknown interpretation or meaning (Heidegger 1962).

Another essential interpretation tool in hermeneutic phenomenology is a clear identification of foreknowledge where the researcher comes to terms with their assumptions and make them explicit (Heidegger 1962). This is not to separate or put those assumptions aside as in Husserl's phenomenology. Instead, it is to be consciously aware of influences, and open to the possibility that pre-suppositions were flawed, or may require adjustment to include new knowledge and perspectives (Van Manen 1990). As Van Manen (1990, p. 38) states, 'the problem with phenomenological research is often not that we know too little, but that we know too much about the phenomenon we wish to study'. Our 'common sense, our pre-understandings, suppositions, assumptions and existing scientific and technical knowledge, predispose us to interpret the phenomenon before we have even come to grips with the phenomenological question' (Van Manen 1990, p. 38).

The extent to which objectivity is possible and to which preconceived ideas or understanding can be set aside when researchers are studying in fields close to their areas of practice generates much discussion in academic circles. However, there is some consensus that making pre-understandings, and foreknowledge explicit can promote research rigour (Pringle et al. 2011).

Further, several authors argue that it is not always possible for the researcher to be conscious of all their own biases as by their very nature they may be hidden (Pringle et al. 2011). To understand situated truth researchers must immerse themselves in the research rather than attempt to distance themselves and expose pre-knowledge and make very clear how conclusions were drawn (Hisarligil 2012; Tuohy et al. 2013).

McCracken (1988, p. 23) cautions that familiarity can be treacherous as the researcher's long-held beliefs become assumptions and actions become habits so that both become submerged beneath 'the surface of consciousness'. Hermeneutic phenomenologists do not see this as a problem. Instead, it is considered not only impossible to set aside conscious and unconscious thoughts, influences, and beliefs, but that previous knowledge may aid interpretations (Pringle et al. 2011). While bracketing and setting aside foreknowledge has no place in hermeneutic phenomenology, the

researcher must uncover taken-for-granted beliefs and actions and demonstrate reflexivity. This suggests a process of self-conscious reflection and explicit self-awareness (Gadamer et al. 2004; Kjällman-Alm et al. 2013; Newman et al. 2010). Thus, I have outlined my foreknowledge in Section 4.4.2.

## **4.2 Research involving people with dementia**

### **4.2.1 Ethical considerations of involving vulnerable people in research**

Appropriately, research, which involves people with dementia requires a full ethics application. Section 10 of the HREC application identifies people with cognitive impairment as having a distinct vulnerability. There seems a persuasive view that the focus of informed consent is about the duty of care to others, rather than the protection of the vulnerable. Proof of consent is often reconstructed into a compulsory, non-negotiable contract-like agreement (Carter 2009). For institutions, there can be a tendency to favour traditional proof of consent as perceived protection against future litigation by participants (Ashencaen Crabtree 2013; Carter 2009). By its very nature, the risk-averse, legally oriented informed consent process also tends to subvert and undermine the egalitarian, respectful, collaborative relationship that lies at the heart of the majority of qualitative research (Carter 2009).

There are several complex and potentially ambiguous ethical matters when involving people with dementia in research. Issues include assessing and proving capacity to provide informed consent to participate, as well as balancing the need to protect vulnerable people and honouring the core values of 'respect for persons, justice, and beneficence' (National Health and Medical Research Council et al. 2007a, p. 1.5; 2007b, p. 9). Key issues debated in academic circles are that of minimising risk while giving the vulnerable a voice, the use of research proxies and respecting the principles and values of the National Statement of Ethical Conduct in Human Research, 2007, and Australian Code for Responsible Conduct in Research, 2007 (Ashencaen Crabtree 2013; Goodman et al. 2011).

Some ethics committees are uncomfortable or reluctant to provide approval to involve people with dementia directly in research (Beattie 2009; Carter 2009; Cubit 2010). Consequently, many researchers intend to include people with dementia, but to overcome the issues of getting approval and meeting timeframes, cast aside their own values and default to the use of proxies such as the family or meaningful carers to provide consent or to act as research surrogates (Dewing 2002; Goodman et al. 2011). While this affords a view that may not otherwise be available, the reliance on surrogates is not without issues. Spousal proxies, in particular, may also be frail, cognitively impaired and elderly, and family proxies have frequently been reported as being stressed by burden and grief imposed by caring for their unwell relative (Mullin et al. 2013). Further, the data gathered is secondary and potentially inaccurate (McKeown et al. 2010).

The use of proxies assumes intimate personal knowledge of the person and unencumbered dissemination to the researcher. This information may, however, be based on the surrogates' knowledge of their relative's past values and preferences rather than the present (McKeown et al. 2010; Sabat 2005). Families may be motivated to report positively as they are concerned negative feedback may impact on their relative's quality of care (Mullin et al. 2013) and reporting ill-being may be psychologically incongruent with their own needs (Vohra et al. 2004). The views of family and staff have also been found to contradict those of residents<sup>3</sup> (Komaromy 2000; Tan et al. 2013).

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<sup>3</sup> To aid ease of reading, the word resident is used interchangeably with 'people with dementia' throughout the thesis. All resident participants included in the study and text had a diagnosis of dementia.

Notwithstanding the difficulties of engaging people with dementia in research, the use of proxies and exclusion of people with dementia from research is incongruent with current discourse. By positioning people with dementia as vulnerable, their rights may be undermined, rendered unable to make personal decisions about the own lives including involvement in research and the potential to discuss their life experiences (Ashencaen Crabtree 2013; Sabat 2005). Exclusion from research can also be considered harmful to the person, discriminatory and controvert widely espoused notions of valuing personhood (Dewing 2002, 2007).

As discussed in Chapter 3, person-centred-care (PCC) was a significant move from 'pathology to people', although the philosophy is not always translating into practice (Dewar & Nolan 2013; Nolan et al. 2006). Similarly, the goals of PCC to value personhood are often not applied in research and people with dementia are excluded from research.

We cannot assume that people, even with late stage dementia, do not have meaning-making ability, and their expression is a fundamental human right and can assist us in understanding their experiences (Dewing 2007; Edvardsson 2008). While appreciating the sensitive nature of involving people with dementia in research, their participation is core to providing a comprehensive understanding of their lived experiences and the influence of the built environment on their sense of well-being.

People with dementia remain one of the most excluded research groups in our community, and while they are the primary users of RACF environments, minimal qualitative research has been done from their perspective (Kitwood 1995; Mullin et al. 2013; Rigby et al. 2010). It is important to hear their opinions, as it is likely that they will have a view that is relevant to the research.

Reliance on traditional methods to demonstrate the capacity to provide informed consent may often exclude people with dementia, with the denial of an essential aspect of selfhood and focussing on a person's losses rather than their remaining capacity (Ashencaen Crabtree 2013; Goodman et al. 2011). Hellström et al. (2007, p. 611) argue that current notions of informed consent are universalistic, exclusionary, and based on what she calls a 'one size fits all' model of deterring consent.

Informed consent is founded on a required minimum of cognitive competence that is assessed in a clinical and non-situational manner, rather than a competency-based approach (Dewing 2002; Sabat 2005). Measuring capacity to consent is often based on neurological tests such as the Mini-Mental State Examination (MMSE), which has little bearing on a person's ability to consent to research (Sabat 2005). The MMSE does not indicate the ability to talk about life, feelings, and lived experiences.

Assessing and proving capacity to consent is not straightforward for people with dementia (Goodman et al. 2011). The demands for designing methods and gaining research approval are a complex consideration of legal and ethical requirements, assessing capacity for consent and participation, adequately proving consent, and demonstrating sensitive research design to protect people with dementia.

The National Statement of Ethical Conduct in Human Research, 2007, updated March 2014, allows for tailored and thoughtfully designed consent alternatives. Section 2, Chapter 2.25 of The Ethics Statement provides for non-traditional consent methods such as 'oral expression' and 'conduct

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While the ambiguity about notions of the RACF as 'home', sense of home was discussed in Chapters 2 and 3, I adopted the term 'resident' consistent with use by the families, staff, and organisation.

implying consent' providing they are appropriate and can be evidenced (National Health and Medical Research Council et al. 2007b, p. 9).

A move from traditional methods to more inventive, person-centred approaches is potentially more appropriate, and increases the likelihood of success as well as alleviating the concerns of others (McKeown et al. 2010). Prominent researchers advocate varying forms of flexible consent that are particularistic, inclusive, context-situated, and building upon strengths (Dewing 2002, 2007; Nolan et al. 2002). Further, as the experience of dementia is unique to each individual, any approach must also consider a range of abilities, and be individually customised.

Several innovative methods for proving consent were identified in the literature. Dewing (2007) argues for progressive consent based on person-centred nursing practices and people's everyday experiences. Ashencaen Crabtree (2013) recommends an unfolding or ongoing consent that minimises risk by building a relationship of trust between all research participants. Nolan et al. (2002) promote an exchange model of consent and participation that values the benefits and perspectives of all participants equally in the research process. These models are based on mutual trust and valuing capabilities, which address vital ethical components of respect, justice, and beneficence.

Consent as an ongoing process is a widely accepted concept. Relatively self-explanatory terms used to describe continuous consent methods include process consent (Dewing 2002, 2007) and progressive engagement (Robinson et al. 2011). McCormack (2002) designed a narrative-based approach to consent, and Ashencaen Crabtree (2013) argues for a verbal consent process where the explanation becomes a conversation and the parameters negotiated between parties.

Consent involving all parties in the research relationship is becoming increasingly more widely accepted. A multi-faceted approach enhances protection during research, minimises risks and alleviates many of the concerns of the family, staff, and care organisation (Beattie 2009). Several scholars identified working collaboratively with the family and staff to both recruit and communicate with potential participants with late-stage dementia as a successful approach (Cubit 2010; Hubbard et al. 2003; Nolan et al. 2002). An additional safeguard adopted in this study was to seek non-traditional consent from the person with dementia as well as traditional proxy consent from one of their close family members.

Notwithstanding moral issues, Beattie (2009) points out that there is no 'gold standard' at this point for proving informed consent. Even when every care is taken, a person's assent or dissent may not be sufficiently explicit to allow research involvement or to adequately demonstrate consent (Ashencaen Crabtree 2013). Scholars conclude that there is no way of judging whether anyone, with or without dementia, is fully informed (Ashencaen Crabtree 2013; Hellström et al. 2007). Therefore, the goal was to ensure maximally informed consent, which assumes that people with dementia have sufficient competency to make decisions about participation (Hellström et al. 2007; Murphy et al. 2005). Hubbard et al. (2003) conclude that judging the capacity to consent should be on a case-by-case basis, dependent on what the participant is being asked to do.

Potential harm can be minimised with a careful and sensitive research design that considers their well-being above the research agenda. Accordingly, processes were developed for the study that honoured and protected the person and was congruent with current discourse about personhood. I carefully demonstrated methods that were sensitive and tailored to the needs of people with dementia to the Ethics Committee, and approval was granted on June 1, 2015.

#### 4.2.2 Recruiting and informed consent processes to give voice to people with dementia

The design of recruiting, consent, and research processes drew on several relevant and successful methods that included people with dementia. Similar to consent methods described above, recruitment was in several stages using a progressive engagement and collaborative approach based on ordinary daily experiences (Dewing 2002, 2007; Goodman et al. 2011; McKeown et al. 2010).

Some of the obstacles to researching people with dementia were overcome by collaboration with family and staff. Dewing (2007) and Nolan et al. (2002) describe research methods that understand knowledge and capacity are situational, and support by others in a familiar environment strengthens the ability of people with dementia. By working within the environment, developing trust and rapport with residents, I was able to create sensitive, tailored means of communicating collaboratively with staff and family for each resident participant. In a recent Australian study adopting a similar approach, potential participants were found to express curiosity about the researcher's presence, providing a natural opportunity to discuss the study in everyday conversations and to recruit in a gentle manner (Chin 2010).

Based on McKillop and Wilkinson's (2004) advice, the invitations, information sheets, and consent to participate forms were buff coloured, with large print format, and short, single sentences. While I designed both a traditional and a simplified version of invitations, information, and consent forms for residents, only the simplified version was utilised once I understood the actual capacity of the residents (see Appendix 3).

Given that people with dementia have a diminished capacity for verbal communication, reasonably clear non-verbal and behavioural cues are considered a suitable form of communication (Clare 2010). Signatures customarily gathered as 'proof' of consent can be either non-verbal or verbal (Dewing 2007; Hubbard et al. 2003). Assent, an important concept in dementia care (Dewing 2007; Hubbard et al. 2003) was adapted in the research, allowing expression of intent even when verbal skills were diminished. I presented the information verbally to the resident in the presence of a family or staff member. This often took place over two or three short sessions so as not to overwhelm the resident. I initialled and dated each point of the consent, which was then verified by a Registered Nurse.

In processes outlined by Dewing (2002) and (Young & Manthorp 2009), a biography was sought from a family member or meaningful carer to identify and recognise individuals' usual signs of consent and assent, communication methods, and signs of ill-being or fatigue. This individualised information aided my interpretations as well as protecting the resident so that research conversations were sensitively delayed or ceased at the first sign of discomfort.

Residents were not approached about the study until research conversations with their participating family member had occurred so that their biography was developed to inform recruitment and consent methods, which were then tailored to suit the needs of each resident.

Several scholars identify the potential for staff bias when assisting the selection of potential participants (Chin 2010; Mullin et al. 2013). A direct recruitment process was engaged to minimise this risk. Rather than guiding selection, staff assisted by identifying unwell residents and overly stressed families. Through my voluntary work in the research setting, described below, I also built rapport and established familiarity with a number of potential participants early in the fieldwork and collaborated with staff and family to determine residents' relative cognitive capacity and well-being.

An aspect of potential power relations identified in other studies was that participants might feel an obligation to participate from concern that care or their relationships with staff could be negatively



affected (Goodman et al. 2011; Hellström et al. 2007). There was also potential that my ongoing presence in the wing as doing voluntary work as described below might have a similar effect on residents, family, and staff sense of obligation to participate. All participants were assured that participation was voluntary and this was reinforced on all invitations, project information sheets, and consent to participate forms. Further, I did not pressure participants to consent and ensured that I maintained friendly social relationships with everybody in the wing, regardless of whether they participated.

People with dementia may be easily confused or distracted in a conversation or research situation (Young & Manthorp 2009). Considerable care was taken to minimise these risks. For example, I used a small notebook so that my interactions with residents were less likely to be confused with staff care documentation processes. I carefully planned every visit so that all materials were to hand, the recording device checked, and batteries charged before entering the research setting to minimise fussing, fumbling, and rummaging which could potentially impair the flow of the conversation or distract the participants.

To facilitate residents' recognition of the researcher, multiple cues including wearing the same clothing and the same striking necklace were worn at every visit. My carefully selected everyday clothing was discrete, not overly bold, formal or with fussy details. A warm coloured, simple floral shirt with plain trousers, dissimilar to the staff uniform was chosen to reduce the possibility of being identified as an authority figure.

The opportunity to share personal stories in a familiar environment, supported by others has been shown to contribute to strengthening self-identity for residents with dementia (Hellström et al. 2007). A study by Hellstrom et al. (2007) which included people with dementia found that if research can be an enriching experience for all involved when conducted in a safe context. Several participants from all groups observed that participating in this study allowed them to share thoughts, opinions, practical ideas, and to have their experiences validated contributed to their sense of worth and well-being.

Indirect therapeutic benefits may have included a sense of inclusion for people rarely given a 'voice' as well as a sense of contributing positively to research with the potential to improve the design of future care homes and the lives of others. The spirit of the research engagement was one of a collaborative approach that valued all involved as equal conversation partners working together for a common goal to make things better for others. The research platform provided all participants with 'permission' to speak freely and the opportunity to talk to an attentive, non-judgemental, and interested listener without time constraints.

### **4.3 A hermeneutic phenomenological philosophical approach to research design**

#### **4.3.1 Immersion of the researcher**

I aimed to stay as close to lived experiences as possible in keeping with ontological notions of Heidegger and Gadamer through an immersion in the research setting. In addition to the research methods described below, working voluntarily in the RACF enabling me to experience the world-of-being-in-aged-care, and to develop deep and comprehensive understandings of lived experiences. Volunteer work included providing companionship, feeding residents, and social conversations, while also allowing for naturalistic observations and impromptu conversations.

My immersion resulted in a deeper experience of the phenomenon rather than a simple narration of events. A single case study provides for deep contextual insights, and familiarity allows an insider perspective of taken-for-granted activities and interactions hidden from much of the community.

It is of course, unrealistic to assume that the researcher can share parallel experiences with residents, staff, or family. Rather, voluntary work facilitated a more thorough understanding of lived experiences within an RACF. Extensive immersion reduced the risk of only capturing 'snap-shots' of how the built environment influenced subjective lived experiences, as well as the potentially artificial view of the research setting due to well-intended actions such as 'tidying-up' before the researcher arrived (Mjørud et al. 2017).

Both the notion of covert observation and the potential to create confusion for resident and family participants about my dual role as researcher and volunteer within the wing were considered. While accepting Abbey's (1995) argument that the participants with dementia may not understand the researcher's reason for being in the wing, every effort was made to keep residents informed about why I was in their place of residence, and I re-introduced myself at every interaction. While full understanding was unlikely by those with dementia, observation was a necessary part of the research to give them a voice, and no harm was apparent.

At a personal level, it was essential to feel that I was not exploiting, but rather contributing to the lives of vulnerable people. Many of the resident participants spoke of loneliness and while it was essential to complete my research, to be kind, and perhaps briefly to alleviate their sense of isolation, which was important to me.

#### **4.3.2 Longleaf; a typical Australian RACF**

While seeking a comprehensive understanding of being-in-the-world-of-aged-care through a pluri-vocal, multi-perspective approach, the scope of the study was limited by time and resources to one wing of an RACF. The aim was to engage with the local and the specific, to create a rich depiction of my immersion into the wing of a typical Australian RACF, rather than to seek generalisable data. This was intended to enable the reader to identify with and relate to the participants and their lived experiences. The aim was that the reader could become familiarised with the characters and setting, ideally allowing for transferability or comparison with other Australian RACFs, and experiences in different long-term care settings.

Of note is that the study is situated in a specific point in time in Australian aged care history, and thus the findings are positioned in this historic and socio-cultural context. Similar studies twenty or thirty years ago are likely to have yielded different accounts of lived experiences, in part because the environment, experiences and expectations of aged care were different.

RACFs were described generally in Chapter 2. The selection criteria for this study of a typical Australian RACF included being over 60 beds, high-care with a likely high proportion of residents with dementia but not designed to be dementia specific, and situated on a co-location site including independent living, low and high-care RACFs. The majority of RACFs are located in urban settings, either a city or regional town. This study is situated in a capital city.

While several participants proposed that the floor plan or layout of RACFs has changed very little since the 1980s, it was essential for currency that the study was in an RACF that was less than five years old. An issue identified in several studies is that over the course of research, modifications or unexpected changes to the built environment were reported as confounding the results particularly

in objective studies (Chenoweth et al. 2014; Schwarz et al. 2004). While not considered an issue in this qualitative study, only maintenance was undertaken.

Pseudonyms were adopted to protect identity. The organisation is referred to throughout the thesis as Aged Care Inc., the site as The Village, the RACF as Casuarina House, and the wing as Longleaf.

The Village has over 2000 residents with a range of accommodation including independent living units, specialist dementia-care units, and eight high-care RACFs. Several of the RACFs in The Village were initially designed as low-care hostels, and later all upgraded to high-care in response to increasing care needs.

Longleaf housed forty residents and was one of five wings within Casuarina House, a high-care facility with 167 residents. Chapter 5 includes a more detailed description of the built environment and interior.

While Longleaf was not explicitly designed for dementia residents, the majority of residents had dementia. At any one time, over 85% of the residents in Longleaf had a diagnosis of dementia, but staff reported many of the remaining residents as 'confused'.

#### **4.3.3 Impromptu and prompted conversations**

While some dictionaries define 'conversation' and dialogue as 'talk', Gadamer uses the term 'conversation' to focus on human understanding and experience rather than abstract knowledge about ideas (Risser 2015; Smythe et al. 2008). Thus, conversations create learning opportunities more significant than could be accomplished by the individual (Baker et al. 2005). Together, conversation partners engage with mutual respect to develop new ways of understanding through relating to one another (Baker et al. 2005).

While the reciprocal conversations were intended to be naturalistic, they were not idle chatter. A Heideggerian phenomenological conversation is unstructured in that it does not follow a pre-organised plan, nor is it unstructured in that there is no clear sense of why we are engaging in the conversation (Smythe et al. 2008). Several authors caution of the delicate balance required to remain open, flexible and engaged while also gently guiding the conversation to maintain sufficient focus and avoid the conversation becoming overly social (Kvale 1996; McCracken 1988; Rubin & Rubin 2005).

In Heideggerian research, we do not 'conduct' a conversation, rather the exchange is more fundamental, and we generally engage with our research participant, to become immersed in each unique conversation, allowing it to unfold without judgement or overzealous directing (Smythe et al. 2008; Young & Manthorp 2009). Every visit to the subject wing, Longleaf was with an open mind and without expectations, letting the participants guide the direction of the research, and demonstrate their own 'normal' as recommended by Chin (2010). In hermeneutic phenomenology, the ordinary and mundane is where there is significance (Heidegger & Hofstadter 1971; Malpas, J 2014). I found that relaxing into the conversation and that rather than being in a formal office or interview room, a familiar setting where participants felt relaxed and comfortable supported the conversation flowed, and most of the questions in the conversation guide were answered without asking and often with little prompting.

As suggested by Berg et al. (2006), I endeavoured to create an atmosphere where participants could respond spontaneously, with minimal structured guidance, a kindly leading and attentive listening to avoid the perception of a threat or challenge to someone with cognitive impairment.

Direct questions requiring memory may induce stress and potentially confuse people with dementia, and also risks a sense of failure if the resident became aware of their confused or inappropriate responses (Young & Manthorp 2009). While several researchers have found a naturalistic approach facilitates a richer narrative and sense of sharing, a special sensitivity is required when vulnerable people are involved (Bevan 2014; Lowes & Gill 2006; Young & Manthorp 2009).

Relationships were formed with all of the participants which departs from the traditional stance of researcher neutrality and detachment. Neutrality was neither achievable nor useful, and building rapport was essential given the immersive research approach and the involvement of vulnerable people.

‘The first condition of the art of conversation is ensuring the other person is with us’ (Gadamer et al. 2004, p. 367). It was important that as the initiating conversation partner, I demonstrated myself as a ‘benign, accepting, curious, but not inquisitive individual who is prepared to listen to virtually any testimony with interest’ (Baker et al. 2005, p. 28; McCracken 1988). For many of the participants, the research situation provided a welcome opportunity when ‘suddenly they have the perfect conversation partner, eager to listen intently to anything that was said’ (McCracken 1988, p. 28).

Focussing on the collaborative relationship and interaction between research participants supported a reflexive approach and provided clues for interpreting the meanings shared by the participants. As recommended by Kvale (1996), when the participants understood that they were not being treated as research subjects but as conversation partners, there can be a higher possibility to feel more at ease and reveal some of their inner worlds.

Young and Manthorp (2009) proposed that understanding a person with dementia who may speak in poetic or metaphorical language might be challenging. I developed a good relationship with participants with late-stage dementia so that by the time prompted conversations commenced, I was usually sufficiently familiar with their style of communication to have a sense of what they were trying to convey if they spoke symbolically or cryptically. When I was not confident that I had clearly understood the residents, I was able to check for possible meanings with their family.

The primary goal of the conversation was to encourage participants to narrate their stories as freely as possible aiding their immersion in the telling of their experiences with open-ended questions. Hermeneutic phenomenologists understand that truth is complicated and relative (Lindseth & Norberg 2004). Factual accuracy was not required. Stories and accounts were accepted as truth, with meaning and relevance to the study (Rugg & Petre 2010). To this end, care to maintain a natural posture and facial expressions, and gestures to signal attentiveness, and non-judgement was crucial. In respect for the sensitivity of the subject and resident vulnerability, I was careful of my use of language and vigilant not to contradict or deny accounts, even in the face of contradictions and information that I suspected to be incorrect.

In addition to socially normative and courteous behaviour such as greeting people by name, I reintroduced myself at each encounter and confirmed ongoing consent to participate. I commenced each prompted conversation with a social conversation rather than immediately launching into the research. I affirmed consent and reminded all participants that I was recording the conversation.

Real-time feedback was shared throughout encounters, and I participated equally in the conversations as well as sharing some of my own experiences. Being able to share initial interpretations and insights provided for rich conversations, was affirming for the participants and created circumstances that facilitated clarification of my understandings. It was likely that the

residents felt more comfortable and were encouraged to respond with more candour than may have been possible within a more traditional research relationship.

Prompted conversations provided an opportunity to gain an in-depth understanding of participants' expectations, perceptions and lived experiences. The majority of staff and family prompted conversations took place in the Activities Room. Resident conversations occurred in their bedrooms to minimise disruption to their day and to reduce interruptions and distractions.

The research setting, resident personal belongings, and photographs were essential prompts in conversations to talk about spaces, places, previous lived experiences, and connection to others. Prompts were particularly useful to initiate or regenerate a conversation when a resident had lost the thread.

Variability in need for prompts and the residents' ways of responding was expected in this cohort. Non-verbal responses, single word answers, detailed anecdotes and lengthy stories were considered equally valued and valid, adding to the richness of the stories and text.

The research approach, with regular and continuous blocks of time spent in the setting, facilitated checking of interpretations concurrently by way of specific questions and impromptu conversations with participants. Reflective questioning in subsequent impromptu conversations presented an excellent opportunity to build on previous conversations and to ask specific questions as gaps and omissions were revealed, promoting a more in-depth understanding of participants' lived experiences. Hence, interpretations were progressively constructed with meanings clarified, confirmed, and negotiated with my conversation partners.

I turned off the recording device to symbolically end research conversations, similar to a technique described by Dewing (2007). I then transitioned into a 'cool-down' conversation about general topics and shared personal experiences, positively affirmed participants' contribution, and expressed my appreciation for their participation and time. For residents, I ensured a smooth transition to another social relationship by gently withdrawing and 'handing over' to a family or staff member.

Extensive research notes were made following each prompted conversation to capture the authenticity and immediacy of the conversations, and other aspects not recorded by an audio device. I focussed on non-verbal communication, facial expressions, body language, apparent mood, and my sense of the participants' well-being. The context of the research environment was noted including noise levels, interruptions, lighting, notional temperature, and ambience to capture the contextual richness. Notes were both descriptive and reflective.

In keeping with a reflexive approach, a general understanding for each prompted conversation was written as soon as practicable following the conversation, before listening to or transcribing the recording. The aim was to capture initial impressions, understandings, and the memory of significant elements. Journal extracts are included in the following interpretive chapters to add detail to the stories, as a record of the evolution and deepening of interpretations, and understanding, and to convey the researcher's emotional and intellectual responses.

Engaging both impromptu and prompted conversations added to the authenticity of the study as well as capturing and mitigating residents' fluctuating cognitive and communication capacities. Impromptu conversations took place during everyday activities where both the researcher and conversation partner were likely to be less self-conscious and the conversation more naturalistic, spontaneous, and less filtered. While designed to be naturalistic, prompted conversations were pre-agreed and scheduled, and there was undeniably a level of gentle guiding, potentially leading to

more filtered and considered responses. Conversation partners were more consciously aware that they were in a 'research situation'.

#### **4.3.4 Discussion groups and follow-up conversations**

The discussion groups were an integral part of the hermeneutic 'loop', described in Section 4.1.6 whereby researcher interpretations are explored with a group of people who have first-hand experience of the phenomenon (Van Manen 1990). In addition to interim testing of interpretations, I offered the participants the opportunity to reinterpret, clarify, add to, or amend both their previous prompted conversations and researcher interpretations.

Given that people with cognitive and communication impairments may be distracted, hard of hearing or uncomfortable in group discussions (Hubbard et al. 2003; McKillop & Wilkinson 2004), follow-up one-to-one conversations were considered more appropriate. The discussion groups and follow-up prompted conversations reduced the risk identified by Gadamer et al. (2004) of the researcher developing overly theoretical interpretations or excessively filtering participants' stories through the lens of their foreknowledge by sharing understandings.

In general, those attending the discussion groups corroborated the findings and resonance was evident in the affirming comments that were made by family and staff about researcher interpretations. As no new information was revealed in the follow-up conversations or discussion groups, research saturation was deemed.

#### **4.3.5 The interpretation process**

Interpretation, which in hermeneutic phenomenology is fundamentally a textual reflection on lived experiences was guided by the approach described by Van Manen (1990). Observations, researcher reflections and impromptu conversation notes, and transcribed one-to-one prompted conversations, discussion group, and follow-up conversations formed the hermeneutic text and a multi-layered process of hermeneutic looping.

Dissimilar to many qualitative approaches, interpretation and research methods in hermeneutic phenomenology are deeply entwined and integrated, and the research process as a whole is interpretive (Smebye & Kirkevold 2013). While several hermeneutic phenomenological researchers outline their interpretive process in sequential, discrete phases, this seemed an overly logical, and linear presentation that attempts to simplify the reality of the more untidy, ongoing, and continuous cycling back, and re-interpreting process in this study. Interpretations in this study commenced immediately and were ongoing and overlapping throughout fieldwork, becoming increasingly enriched by participants' interpretations, reflective questioning, and hermeneutic looping.

Thus, interpretations can be pre-reflective, and hermeneutic looping commenced during the research conversations where feelings and thoughts were shared, and understandings constructed and co-constructed through language (Dahlberg et al. 2001). A phenomenologists' primary interest is in the person's experience and how they make meaning of the experience, rather than the phenomenon itself (Bentz & Rehorick 2009; Wagstaff & Williams 2014).

This reflexive use of conversation and stories makes explicit that conversations are shared interpretations, not a neutral exercise, but likely to reflect existing societal values, aspirations and to some extent, the values the conversation partner may perceive their co-participant wants to hear (Gadamer et al. 2004; Miles et al. 2013). Both the listener and the speaker interpret what was said, often continuing to converse to refine and negotiate interpretations and understandings of lived experiences collaboratively in real time (Dewar & Nolan 2013; Doyle 2012).

While hermeneutic phenomenological or single case studies utilising qualitative narrative-based enquiry and observations generally have between one and five participants, the outcome was thirty-one prompted conversations, two discussion groups, seven resident follow-up prompted conversations and hours of impromptu conversations, observations, and reflections (Djivire et al. 2012; Hellberg et al. 2011).

All prompted conversations, discussion groups, and resident follow-up conversations were recorded. The recorded conversations were transcribed verbatim as close to the day of the conversation as practical. As one-to-one conversations and focus groups provide large amounts of rich narratives per participant (Creswell & Creswell 2013; Kvale 1996) the approach generated a large volume of text. The challenge was to select the most important features to address the essences while omitting excessive detail. The objective was to reflect critically and interpret the stories and symbolism that participants used to convey their lived experiences and emphasise the experiences and symbolism that I interpreted as the most significant, evocative, and meaningful.

The hermeneutic text was then interpreted in the context of the overall understanding of the situation of being-in-the-world-of-aged-care while continuously moving backward and forward between the parts, that is, the individuals' stories, and the whole. The transcripts were read repeatedly to develop an overall sense of the context and lifeworld experiences, before evolving into main clusters of related meanings.

The clusters of meaning were annotated, and quotes and accounts of lived experiences that 'touched the researcher' were highlighted in the transcribed texts, and further reflections written in readiness for the discussion groups and follow-up conversations. This involved looking at the whole experience and making decisions about the things that mattered most, and that influenced how the person thought of themselves or the place they were in (Paley 2014; Wagstaff & Williams 2014).

While meanings do not have to be repetitious, it is not to say that repetition was not meaningful in this study. Repetitive powerful imagery and symbolic stories that were at times about fear and loss touched the researcher and were crucial for developing meanings.

I continually reflected on the 'thickly rich' descriptions with ongoing interaction and hermeneutic looping with the research participants, supervisors, peers, and the literature. Fostering an inductive approach is particularly important in hermeneutic phenomenology where the researcher needs to set aside what they are looking for initially to be led by the participants and be sensitive to what the stories and text tell them (Laverty 2003; Tuohy et al. 2013).

It is then the acts of writing and re-writing, interpretation and re-interpretation that are intended to draw us deeper into our comprehension of experience, and our experience draws us deeper into writing, into the language to facilitate an understanding or seeing of something new in what is already taken-for-granted and to find meanings (Smythe et al. 2008).

Impromptu conversations, discussion groups, and follow-up conversations provided additional opportunities for re-interpretations that were essential elements of the 'loop'. Ongoing, multi-layered looping served to evolve and further deepen understandings, and I addressed my foreknowledge continuously as recommended by Dahlstrom (2010) throughout the interpretive process to reduce the risk of subconscious filtering. In this way, contradiction, omission, and incongruence, as well as coincidence, were attended to in the research, and multiple simultaneous, interpretive possibilities were considered normal even welcomed as evidence of authenticity.

About halfway through the fieldwork, I presented initial findings and interpretations at the national Australian Association of Gerontologists conference in November 2015. The presentation was an early interpretation tested with a knowledgeable audience of several professions and academics from various fields. It was an opportunity to 'loop' preliminary interpretations to peers, facilitating an early consolidation of my understandings of the stories of lived experiences I was gathering, and a check for resonance. The experience proved beneficial as the feedback was excellent, clearly demonstrating a reverberation between my interpretations and the lived experiences of the phenomenon by others. This facilitated the refinement of my research approach in subsequent prompted and follow-up conversations and the discussion groups.

The reflexive process included discussions about alternative interpretations, and the transcripts were revisited to expose any discrepancies in my interpretations, whether meaningful aspects had been omitted, or the meaning exaggerated to confirm or amend earlier interpretations and provide transparency about how methodological decisions were made (Feldman 1995; Håkanson & Öhlén 2016; Kamler & Thomson 2006). At times, alternative interpretations were included in the thesis recognising that a complex and profoundly personal research topic may have multiple valid meanings between individuals and the three participant groups.

#### **4.3.6 An overview of the research process**

Fieldwork or my immersion in the wing was completed over ten months while working full-time from 1 June 2015 to 31 March 2016. I spent blocks of four to six hours, two to three days a week from Friday to Sunday in the wing including different times during the day and night. In addition, I made frequent, irregular shorter visits throughout the week.

The study involved three research participant groups: staff including facility Care Managers, the family, and people with dementia described in more detail in Section 4.4.2.

Each research visit commenced with a conversation with the Registered Nurse (RN) about resident well-being and changes such as deaths, hospitalisations, admissions of new residents, or significant events that may have taken place in the wing or individuals' lives. If a resident was deemed unwell or fatigued, a social rather than a research conversation took place.

I then noted the number of visitors in the wing, and the weather, time of day, and general ambience of the Longleaf environment.

While observations and impromptu conversations took place across all shifts and in all spaces except bathrooms, the prompted conversations were less flexible. Prompted conversations with family and staff took place during the day and were mostly in the Activities Room. Two family participant prompted conversations were in The Village Café, The Banksia Centre and one in a spouses' unit on site.

Prompted conversations with residents took place in their bedrooms, except for one resident who was in a living space. To support the residents' ability to participate, prompted conversations were organised for the period when they were likely to be most alert between mid-morning after their showers and mid-afternoon before they fatigued.

The fieldwork was seven progressive and logical phases. While phasing outlined below is suggestive of linearity and autonomy, there was considerable overlap, and volunteer work continued throughout all phases of the study.



**Phase 1-Warm-up, rapport building, and volunteer work immersion**

Phase 1 included completing a volunteer's induction program before commencing fieldwork. Potential participants were identified by reading their clinical notes and 'life stories' that had been documented by staff or families upon admission to develop a short-list of potentially suitable participants. All participants' clinical notes included a medical diagnosis of dementia, and as Longleaf was the most high-care RACF on site and considered by the organisation as a final stage wing, all residents were identified as having late-stage dementia. This short-list of potential participants was checked and confirmed by the Care manager for Casuarina House.

**Phase 2-Recruiting and seeking consent**

It took over a month to build sufficient rapport and familiarity with the routines of the wing before I initiated recruitment.

Managers and RNs were accustomed to involvement in research due to the aged care organisation's affiliation with a university, but care staff and family had no previous experience. Families and staff were eager to participate, and have their stories heard but were juggling many priorities, and between two to five postponements of scheduled prompted conversations were common.

As discussed in Section 4.2.1, there was no certainty that residents were fully cognisant of the consent process, but several discussed their willingness to be involved in a University study, and to 'help others'.

**Phase 3-Impromptu conversations**

Impromptu that is everyday conversations took place with all participant groups: aged care managers, staff, family, and residents, throughout fieldwork.

Reflective questioning during impromptu conversations was often used to build on previous conversations and to promote a more in-depth understanding of participants' lived experiences.

**Phase 4-Prompted conversations**

Prompted conversations took place with all participants. They were scheduled, one-to-one conversations using cues and 'prompts' in the environment to initiate conversations with all participants. As discussed above, I guided the conversations and allowed them to unfold rather than asking a series of structured questions.

Staff were the first to be engaged, with some overlap with family prompted conversations, and then residents once their biography had been developed.

Staff prompted conversations were minimised to thirty to forty minutes to reduce the impact of the research on resident care. Family prompted conversations, which included a resident biography, were longer, taking from 45 to 90 minutes. The resident-prompted conversations ranged from nineteen minutes to an hour, although the majority were about thirty minutes.

**Phase 5-Preliminary interpretations and Hermeneutic Loop**

While interpretation was continuous throughout all phases, a more intensive interpretive period commenced at the conclusion of all thirty-one prompted conversations and fieldwork was temporarily ceased. Given the residents' cognitive impairment, I maintained an ongoing relationship by continuing to visit, enjoy social conversations, and engage in volunteer work, but did not conduct research.

### **Phase 6-Follow-up Conversations with residents, and Discussion Groups with family and staff**

My original intention to hold separate family and staff discussion groups proved challenging due to staff rosters and random family visiting times. Consequently, two combined discussion groups, one on a weekday and one on the weekend, were held. My concerns that family and staff would filter their responses in front of each other proved unfounded, and frank and open conversations took place.

Discussion group attendance was slightly disappointing as there was considerable interest expressed, but Discussion Group 1 had only four attendees including three staff Care Service Employees<sup>4</sup> (CSE) and one family participant. Discussion Group 2 had four attendees, two family participants and two staff: one CSE and one RN.

Several participants who were unable to attend contacted me privately to contribute to the research. Despite relatively low attendance, the research outcome of the discussion groups was productive and informative.

The discussion group commenced with an informal presentation of my preliminary interpretations, followed by an open discussion within the group. I focused on clarification of meanings and seeking confirmation of related lived experiences rather than challenging their stories and views.

Follow-up conversations of between ten and thirty minutes duration took place with seven of the nine residents assisted with clarification of meanings. One resident's health had diminished rapidly, and a follow-up conversation was deemed inappropriate. Another died three weeks after the prompted conversation.

### **Phase 7-Cool down and withdrawal**

A cool-down period including a gentle disengagement to minimise research abruptness was considered an essential quality of a respectful approach. Being employed on the same site as the subject wing allowed a relatively lengthy withdrawal in which no further research took place and conversations were social. I held a thank-you morning tea for staff and family, and residents received a hand-written thank-you card and flowers.

#### **4.3.6 Further ethical considerations and reflections**

Participant well-being was always prioritised over research outcomes and agenda. Ethical concerns regarding increased susceptibility to stress by people with dementia were considered, and all possible precautions were taken to minimise discomfort and create a conversational situation. No distress was detected during conversations. On several occasions, there were signs of fatigue or loss of focus, and the research conversations gently and immediately ceased.

In the eventuality that a participant became emotionally distressed, protective mechanisms had been developed. An RN monitoring the resident participant while the research conversations were occurring, and interceding should any signs of distress occur to minimise any potential long-term harm arising.

The same sensitivity was extended to all participants to ensure minimal negative impact. Previous studies identified staff concern that complaints or adverse reporting may affect employment conditions or relationships with other staff (Haesler et al. 2006). Organisations can be uneasy about potential adverse reporting on the public image of the RACF (Munn et al. 2008). Both staff and the

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<sup>4</sup> Also referred to as care staff, personal carer or carer

organisation were assured that this study would not assess or report on organisational procedures, staff performance, or quality of care provided.

Families expressed nervousness in other studies that potential complaints or negative reporting may unfavourably influence the care of their relative (McCarty 2011; Sandberg et al. 2002). All participants were assured of confidentiality and advised that they were free to withdraw from the study without the need for an explanation at any time should they have concerns.

Participants had the opportunity to choose a pseudonym to protect their identity. Most participants independently chose a pseudonym, while others preferred the use of their real name as they saw no need for anonymity when they had freely opted to participate. Several residents identified with their preferred name rather than their formal name in everyday use and chose this as their pseudonym.

With regard to overall anonymity, it was possible that participants or the organisation may be identifiable in researcher photographs. The Care Manager of the facility and participants were shown all photographs with the opportunity to screen or refuse individual photographs for publication or presentation purposes. The right to veto the use of photographs without explanation was honoured, and all external street views were excluded at the request of the Care Manager.

Careful consideration was given to the potential issue of elder abuse expressed to or suspected by the researcher during the research. While my responsibilities and mechanisms available to report elder abuse were established as part of the research design and ethics process, no abuse was suspected while I was in the setting.

The research was carried out within the parameters of the ethics approval, with some minor changes to the research design and plan. Sourcing the architectural drawings and brief were challenging and delaying. Eventually, the planning approval and working drawings were obtained directly from the Local Council.

My original intention was to include the Chief Executive Officer (CEO) and the architect of the RACF in the study to discuss their perceptions of the design intentions and the resulting building in regard to enhancing lived experiences of residents living and dying with dementia, their family, and care staff. While the CEO approved the study and access to the briefing documents and drawings, he declined to be directly involved in the research.

Further, once I obtained the drawings, I found that the architectural firm no longer existed, and the architect was uncontactable. The architects' and the CEO's involvement were not a significant aspect of the study, but it may have been useful to understand the rationale for the layout, in particular, the large, central dining room and double-loaded corridors described further in Chapter 5.

I had also intended to analyse the architectural brief, but there was no formal briefing document. Instead, there was a series of briefing emails between the architect and CEO of Aged Care Inc. In my professional experience, I found that this is a relatively common occurrence in the design of RACFs especially when the architect has designed RACFs for the organisation previously. Copies of the briefing emails were provided to me by the Aged Care Inc. Property Manager, providing sufficient information for my analysis.

Other minor changes to the research design include an initial intention to use photographs of residents interacting with staff and family as prompts in conversations, but during my interactions with residents, I identified that this was potentially confusing and beyond their cognitive capacity.

Fieldwork became extended through part-time enrolment allowing more time for reflection, to observe change over time and to build rapport slowly, but it also increased the risk of participant attrition in a frail population.

My research plan was designed for flexibility as had been advised by several researchers in a similar context (Chin 2010; Goodman et al. 2011; Hubbard et al. 2003). Both recruitment and prompted conversations took longer than expected. Several potential resident participants became unwell or died during recruitment. Families visits were, at times, irregular and staff shifts were variable. Building initial rapport was a lengthier process than expected.

During the research process, several prompted conversations with staff were postponed multiple times when the wing was short-staffed, or an emergency had arisen. Some staff conversations took place in two or three instalments when the participant was called away during a prompted conversation.

Family conversations were frequently re-scheduled, and two family members who expressed interest in participating did not return the consent forms. In addition to poor health, there were several occasions when I arrived for scheduled conversations with residents to find they were in the hospital, on an outing, had visitors, or were showering. There were many weekends when three or four scheduled prompted conversations were postponed. Further delays were caused by several 'shutdowns' due to gastroenteritis or other infectious outbreaks in the subject RACF.

#### **4.4 Introducing the world-of-being-in-aged-care**

##### **4.4.1 Introducing the conversation partners**

The selection of participants was neither random nor purely purposive except that all resident participants were situated in a typical RACF and had a diagnosis of dementia.

The residents were aged from 73 to 95, with the majority aged mid-eighties to early nineties. Their length of stay varied from three months to two years and ten months. To ensure post-admission stress was not a factor in confounding findings, I only recruited residents who had lived a minimum of eight weeks in Longleaf. Residents are introduced in more detail as part of their stories in Chapters 5, 6, and 7.

To ensure family participants were relatively familiar with the built environment and participant residents, I only recruited significant family members who visited a minimum of once per fortnight. The family participants were engaged, committed to their residents' well-being, caring and responsive people and the rapport established in our research relationship was natural and warm.

The selection criteria for staff included those had worked in the wing for a minimum of two shifts per week for eight weeks so that they could be considered relatively familiar with the built environment and residents. The participating staff had worked in Longleaf from six months to two and a half years, and in aged care from six months to 45 years. As staff and staffing ratios varied at different times of the day and week, I recruited staff participants from weekday, weekend, and evening shifts to provide a comprehensive perspective. Appendix 9 includes a brief biography of each family and staff participant.

Recruiting and retaining frail, older participants was an anticipated challenge. Participant attrition due to declining communication capabilities, deteriorating health, or death was to be expected in this cohort. Twenty-one residents in Longleaf died during the fieldwork period, the majority of whom were not involved in the study. One resident, Fred, died after his wife had consented to

participate in the study but before the prompted conversation took place. Two residents, Mary and Elsa, died following recruitment and prompted conversations with their family members but before their own prompted conversation. Another resident, Tom, died following our prompted conversation but prior to a follow-up conversation.

The research plan outlined recruiting 6-10 staff and residents, and 6-12 family participants to achieve a minimum of five participants in each group. The outcome was two Care Managers who were both RNs, eleven staff participants including two RNs, an occupational therapist, a physiotherapist, a recreation officer/CSE, six CSEs, nine residents and nine family participants, including one husband, three wives, and one adult son and four daughters.

An unexpected bonus in the milieu of aged care where staff turnover is high was the opportunity to include three long-term staff who had worked in the previous nursing home replaced by Casuarina House. They provided comparisons between both facilities as well as information about the design intentions for Longleaf and the extent of consultation with staff.

#### **4.4.2 Introducing the researcher and my foreknowledge**

In Section 4.1.6, I discussed the hermeneutic phenomenological concept of foreknowledge, which attempts to expose the potential for influence on research design, engagement with participants, and personal filters that may have biased my interpretations. Together with the Preface, my foreknowledge below also introduces me as a participant in this study.

My architectural training and professional background colour the way I experience, understand, and assess a physical and social environment. I know directly of the balancing of numerous complex and at times, contradictory factors and constraints affecting architectural processes. These include budgets, multiple stakeholders with potentially conflicting priorities, legislative requirements, time constraints due to fee and market competitiveness, and site characteristics. Foreknowledge of what is required to produce a building is likely to have filtered by my understanding of building outcomes and participant interpretations of the built environment.

I have witnessed at times, an apparent lack of consideration during the design process of the needs of people inhabiting RACFs, and the privileging of aesthetics over creating spaces for quality lived experiences. I have been an employee in architectural offices where I worked on large RACF projects including several that involved specialist RACF architects. I saw first-hand how little time was spent in the briefing process or trying to understand the subjective needs of those who were to live, work, and visit in the RACF.

The work was directed by the CEO of the aged care organisation, and the brief based on prior in-house projects, and the need to maximise beds. Further, the designs particularly the floor plan were based on projects completed previously by my employer.

The language used in my workplace suggested that RACF design is 'not really architecture', not glamorous or exciting, a documentation process rather than an opportunity to create spaces that enhance well-being. While acknowledging these are value judgements, they may have nonetheless influenced my interpretations. It is from my practical experience as an architect that I make several assertions about the built environment and the design process of Longleaf especially in Section 5.1 and 5.2.

Thus, my professional experience may have created prejudice towards interpreting the design of the built environment in ways that are at times more and others less forgiving than researchers in other fields of expertise. The way I think about building design and how people experience buildings will

be through the lens of someone who ‘thinks like an architect’, and therefore different from the way nurse or psychologist researchers will have filtered their research interpretations.

Since commencing my PhD, I have developed a comprehensive understanding of issues related to aged care with extensive research in the areas of environmental, palliative, and aged care provision, clinical knowledge, policy and legislative requirements, and organisational, social, political, and historical issues. Reading included peer-reviewed publications, analysis of Productivity Commission, and AIHW Reports, Aged Care Design Guidelines, and attendance at several conferences. While of course, this is expected of a doctoral student, it is acknowledged as likely to have influenced interpretations.

My employment as a Research Fellow, which was described in the Preface, provided insights into organisational practices and understandings of the aged care system of funding and care provision, although separate from my PhD study may also have influenced my interpretations.

Both my professional and personal experience became the point of departure from which my questioning, understanding, and interpretation began as I entered the being-in-the-world-of-aged-care, as well as the way I designed my research.

#### **4.4.3 Introducing the research voices**

In the same way that people, environment, and care are inseparable, the telling of residents’ stories, was not separable from that of the staff or families. While I fore-grounded the residents’ stories as they are the most vulnerable and most affected by being-in-the-world-of-aged-care, a pluri-vocal approach incorporating and entwining the voices of resident, family and staff participants was adopted to achieve a shared account. Presenting their narratives as stories was intended to achieve my aim to give voice to the participants, especially people with dementia, and find a way to engage with the reader, and in the future, architects and those involved in providing aged care.

Stories are a powerful and effective way to engage and communicate information (Kimmel 2013). The stories build a rich, complex, multi-faceted, and integrated picture from the perspective of the situated participants and are a valuable tool for illuminating how they try to make sense of their world (Cohen & Mallon 2001; Kimmel 2013).

Multiple participant perspectives gathered through the prompted, impromptu conversations, and follow-up conversations, and discussion groups were threaded together. The stories depicted in the following chapters are in and of themselves an interpretation. In order to write the stories, I selected the most ‘touching’ aspects of participant accounts, condensing, weaving together, and making collaborative decisions about which parts mattered the most.

While the stories are grouped within chapters and may appear as fragmented single case studies, there was, of course, considerable interconnection, overlap and similarities as well as differences between the stories. Headings were essential to give some structure to the thesis, but given the innate complexity of humans, it was unrealistic to expect any story of lifeworld experiences to fit neatly under a single, simple heading.

The depiction of participants’ voices is essential in situated research but requires careful consideration. The neutral position typically employed in scientific writing can at times render the participants’ voices dull and distant rather than warmly human, touching, and vulnerable. Correcting or paraphrasing quotes increases the risk of deadening the essence and tone of the stories, rendering them dry and meaningless. Verbatim quotes are used in the interests of naturalism and authenticity, providing a genuine representation of participants’ accounts. Numerous and sometimes lengthy

quotes were incorporated providing the richness of pauses, hesitations, word-finding struggle, tone, and repetition to convey genuineness and enhance the persuasiveness of the text.

Initially, I was uncomfortable using verbatim quotes as many include colloquialisms, grammatical errors, stutters, and considerable repetition. Residents were often distracted, fell asleep mid-sentence, and lost track of the conversation or their train of thought. The residents' fluctuating mood, physical and mental health, and cognitive and communication capacity added further complexity. It was reasonably common for residents to contradict themselves, report varying lived experiences or changeable emotional responses to the same event. They regularly confused facts about time, place, and people.

As each human is unique and their understandings always interpretive, there are several significant conceptual challenges when researching and interpreting the elusive phenomenon of lived experiences in the-world-of-being-in-aged-care. One difficulty is how to interpret their use of language. Of particular relevance in this study, is the participants' use of the terms 'environment', 'place', and 'space'.

Throughout this study, participants frequently used the word 'environment' loosely to mean the environment as a whole; the arguably inseparable notion of the care environment, built environment and lived experiences within the RACF setting generally. They often used the term 'place' to describe the setting of lived experiences and space referred to contained, bounded spaces or rooms in which events occurred. While the terms are used in specifically defined ways in hermeneutic phenomenology and human geography literature, I adopted the participants' interpreted meanings and way of using the terms while constructing their stories and the texts.

The thesis is also the story of my own lived experiences through the immersive methods temporarily situating me in being-in-the-world-of-aged-care. The intention was to demonstrate my in-depth engagement as a research participant and the reflective development of my thinking.

Rather than isolate the voices of the participants from the researcher, three voices were interwoven. Thus, in addition to the voice of the participants and researcher as scholar, there is a third voice, that of the researcher as participant, a more subjective voice that includes reflective journal excerpts. At times, these extracts were direct accounts of events, and at other times, they were reflections following the event.

Situating the research, including my personal perspective, presented some challenges. One that I found initially difficult was the use of the first person. Arguably, writing in the first person is a tool that situates the researcher in the research and is in keeping with both a hermeneutic approach and collaborative methodology. However, there are many critics of the use of first-person, in particular, quantitative researchers, as it is perceived to infringe the values of objectivity and typical use of dominant third-person paradigms (Haraway 1988; Shumack 2010). Haraway (1988), however, advocates for the use of first-person as it acknowledges a temporality and spatiality that allows the researcher to be explicitly present and accountable.

There is increased risk, however, in the use of first person and over-reliance of personal and subjective reflections. Excessive use of 'I' and 'my' may cause the reader to perceive research accounts as recollections and memoirs rather than real-time interpretations and trustworthy research. To this end, first person was used judiciously, attempting to maintain a balance between my voice and participants' voices to facilitate the integration of a reflexive, collaborative story.

In addition to grappling with the problem of structuring interwoven stories, was the need to present the different 'voices' clearly. The voice of the researcher as a scholar, which forms the bulk of the thesis is written in the Calibri font. The voices of participants are presented in *Calibri italics*, and the voice of the researcher as a participant is written in the *Lucida handwriting font*.

The quotes used throughout the following chapters identify whether they are resident, family, or staff. Impromptu and prompted conversation quotes are indicated locating the research context in which the lived experience was shared.

#### 4.4.4 Discussion

This chapter has introduced core concepts of a hermeneutic phenomenological philosophical approach, provided the rationale for this approach, and described the research design. The need for a sensitive and innovative approach that was collaborative and naturalistic to form links between the reader's lifeworld, and the more obscured lifeworld of people living and dying with dementia in an RACF was demonstrated as crucial. Further, a situated, narrative-based, and immersive methodology was demonstrated as potentially the most successful way to engage with people with late-stage dementia.

Notwithstanding the sense of moral obligation to include people with dementia directly in the study, issues in recruitment and proving capacity to consent to participate were addressed. The careful research design then demonstrated how the processes were developed to minimise risk, providing a case for how, on balance, the benefits of participation outweighed the potential for harm.

Without a comforting proscriptive method to provide easily recognisable research trustworthiness, rigour, and authenticity, it was essential to detail the methods as well as provide an audit trail for fieldwork and interpretive processes as justification for the employment of less traditional inter-subjective research conversations, and personal reflections.

Finally, this chapter outlined the selection criteria and introduced the participants and the method for giving voice to the participants. Early interpretations made apparent three main clusters of meanings that later notionally formed the basis for the following interpretation chapters. Chapter 5 relates to participants' lived experiences and meaning-making of feeling connected to place and the physical RACF and trying to make sense of where they are the world. Chapter 6 focuses on participants' lived experiences in connecting with the self and being-in-the-world-of-aged-care, and who they are in that world. The core of Chapter 7 is about the experience of dying within the-world-of-being-in-aged-care.



## CHAPTER 5: 'BELONGING' AND PLACE

Chapter 4 outlined the hermeneutic phenomenological philosophical and research design approach adopted in this study. While Chapter 4 started to acquaint the reader with the RACF setting and the participants, the goal of the next three chapters is to draw the reader further into the lived experiences of being-in-the-world-of-aged-care. The focus of this chapter is the physical RACF environment and the influence on where residents understand themselves to be in the world, and how family and staff comprehend the built environment.

Section 5.1 analyses the architectural briefing process and drawings to start to develop understandings of the intentions of the designers and administrators, in relation to the quality of the participants' lived experiences. Section 5.2 describes the built environment of Longleaf through my voice as architect researcher and participant but more importantly begins to articulate the participants' interpretations of the built environment.

The remainder of Chapter 5 tells the stories of three of the residents: Maree, Marg, and Jean. Section 5.3 explores ageing-in-place outlined in Chapter 2, how the concept is translating into practice and the effects on Maree's ability to understand where she is in the world. Section 5.4 focusses on how Marg understands spaces and how she tries to anchor herself within the RACF. The influence of the built environment on residents' ability to place themselves is told through Jean's story in Section 5.5. The concluding section is a discussion about interpretations.

### 5.1 The architectural brief and drawings for Longleaf

The architectural brief is an important document providing essential information for the architect and usually describes functional as well as qualitative building requirements (Markus & Cameron 2002). It is 'most frequently the opening dialogue for a design project' and generally describes what 'a particular building should be like' and can be seen as a set of intentions (Markus & Cameron 2002, p. 32). Briefs evolve and are referred to throughout the design and architectural documentation process as a measure of meeting the needs of future building users.

Briefing processes vary between individual architects, clients, and organisations (Markus & Cameron 2002). At times, the brief is little more than a list of room and functional requirements, but it can also be a detailed and descriptive set of aspirations for the quality of life of people residing, working, or visiting a building developed collaboratively between the client or building user-group and the architect.

However, there was no formal brief provided to the architects for the design of Casuarina House. Instead, briefing occurred through a series of emails and meetings between the architect and the Chief Executive Officer (CEO). The property manager for Aged Care Inc. provided the documents with the CEO's permission. While the correspondence records were incomplete, the story of how Longleaf was designed was sufficiently understood for the thesis through the notes, drawings, and staff accounts.

The focus of the notes for Casuarina House was about functional requirements and minimum spaces for staff to carry out tasks, the size of rooms and number of beds required, servicing requirements, and the budget. The resulting building had conformity and uniformity imposed by minimum bedroom sizes, the provision of minimum sized bathrooms and toilets, and health and safety requirements.

There were few qualitative notes, but these were at times, vague and with minimal detail or explanation. *'Provide for bedrooms that are private'*. *'The building must provide for safety but not look like a hospital'* (Notes from Aged Care Inc. property manager, undated).

The primary qualitative requirement within the briefing notes for Longleaf was that the design is *'non-institutional'*. Rather than describing the desired characteristics of the building, the CEO provided an *'unbrief'* to the architect of what Casuarina House was not to be. As discussed in Chapter 3, this commonly used linguistic practice, describing what something is not, presupposes that somehow the designer knows the aspired to quality.

Three staff who had worked in the nursing home that Casuarina House replaced reported that they *'heard that Casuarina House was supposed to be designed like a hotel and a hotel consultant designed the interiors'* and *'goodness know why they wanted it to be like a hotel, they are such lonely places'* (Lyn, staff-OT, impromptu conversation (IC), 28 August 2015)? Another staff member did not know if it is true but believed that Longleaf was designed like a hotel *'because they didn't want it to feel like a nursing home and I think it's why we've got that bar thing for the nurses' desk'* (Jan, staff-RN, prompted conversation (PC), 28 August 2015).

In the absence of communication with the architect or CEO, it was not possible to determine whether the hotel concept was a response by the architect to creating a *'non-institutional'* environment or driven by management. In any case, the nurses' station in the dining room and bar in the activities room were the only hotel-like features I was able to identify. There were, however, no notes in the briefing emails to explain the intention or how the qualities of a hotel were expected to meet the residents' needs.

While briefing documents are reasonably expected to communicate important characteristics of potential building user groups and their lives, the briefing notes for Casuarina House had no reference to dementia or the trajectory of the illness. Before spending time in Longleaf, I had not understood that the majority of residents would be immobile, wheelchair bound and that many would be non-verbal despite my previous RACF design experience.

There was also no mention in the briefing notes of the predictably high care needs and mortality, and the need to remove bodies after the death of residents. Despite twenty-one residents, dying in ten months of fieldwork, which staff reported as *'normal'*, death and dying were notably omitted in the briefing notes.

While the three staff participants who had worked in the previous nursing home provided examples of issues especially regarding designing for dementia and dying that they believed were foreseeable and could have been avoided with their input, they indicated that they had not been consulted. Problems included *'Up and down corridors, that's all they've got to wander which is not good for them [people with dementia]'* (Jill, Care Manager), and bedrooms that are *'too small for anyone but the residents'* (Lyn, staff-OT). Jan who had been the Care Manager of both the previous nursing home and Longleaf during the first year of operation made several criticisms. *'When someone dies, you have to go past all the bedrooms and out through the dining room'*, *'no gardens, they are really important'*, *'the dining room, actually the whole wing is too big, especially for the dementias and could be at least halved'* and *'the colours are too same same for dementias'* (Jan, staff-RN, PC, 28 August 2015).

Despite the contemporary colour scheme described below and the recent construction of Casuarina House, the design, predominantly the floor layout was fundamentally unchanged from the hospital-based models of the 1980s, arguably with little reference to advances in environmental research over

the last thirty years. As the Care Manager said, 'I've worked in a number of residential facilities, and they've been very medical model in the way that they've been designed. This [Longleaf] is little different from the "racetrack model"<sup>5</sup> where I worked in the eighties. The eighties! Not much has changed' (Jill, Care Manager, prompted conversation (PC), 17 July 2015).

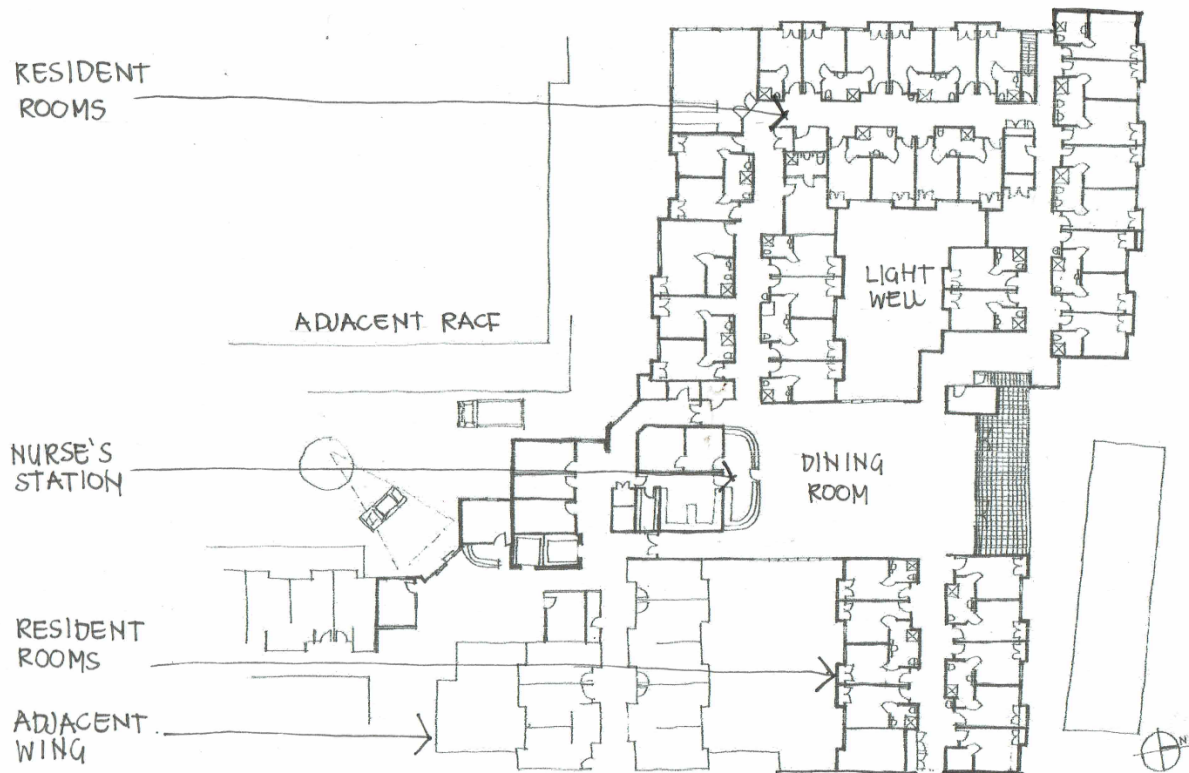


Figure 5.1 Longleaf floor plan: Showing layout of Longleaf with large dining room and long corridors in 'U' shape. See Appendix 10 for a larger floor plan, and sections drawings scaled 1:200.

The entrance to Longleaf was directly into the central living space. The dining room, as the participants called the space, was 20 metres long and 12 metres wide. While a domestic living room varies in size from 20 to 30 square metres, the Longleaf dining room was 240 square metres. The depth of the dining room meant that natural light and sun only penetrated the area closest to the deck. The building was air-conditioned, and due to the size and orientation, the dining room permanently required artificial lighting and 'there's no breeze, no fresh air' (Lyn, staff-OT, IC, 20 July 2015). The light and temperature were the same every day regardless of the weather outside.

The dining room seemed to be the only living space available for resident and family use. Although the early concept drawings for Longleaf included an additional smaller living room with an attached sunny and sheltered outdoor deck away from the main dining room, this was deleted before construction. The outcome maximised the number of bedrooms in Longleaf and likely minimised staffing ratios as surveillance of residents was simplified in a single communal space. This is a typical driver of the design of large multi-purpose living spaces in many RACFs (Hov et al. 2013; Lee, S. Y. et

<sup>5</sup> 'Racetrack model' is a colloquial term used to describe endless or circular corridors with no dead-ends where people with dementia were able to wander safely (Brittain et al. 2017). There are mixed but predominantly negative findings about the model and the connotations of 'wandering'. Fleming, R and Purandare (2010) argues the evidence to support purposeful walking for people with dementia as more life enhancing.

al. 2016). It also meant, however, that there was no choice of different living spaces for different resident needs or activities.

A 'u'-shaped corridor side with 31 bedrooms ran directly off one side of the dining room. Another shorter corridor with nine resident bedrooms extended from one side of the dining room. All the corridors had a bedroom on both sides, which together with the homogeneity of wall and door colours added to residents' inability to identify their bedroom. *'I think it's a problem. You've got big open areas for the dining room, and you've got all the rooms and corridors coming off like a satellite, but people get lost'* (Donna, staff-physiotherapist, PC, 6 September 2015).

The residents' bedrooms were single-bedrooms except for one double room. Eleven residents had private ensuite bathrooms; the remaining residents shared a dual-access ensuite. The bedroom and ensuites layouts were identical except for mirror-reversing of the floor plan for bedrooms with shared ensuites.

My preliminary impression was that of a building that does not seem to be working for residents, families, or staff. *'The structure and layout of the wing read as institutional. I feel a little disoriented, and the bland, homogenised colours offer little guidance to find my way. I've now been in the wing for over a month but felt minor panic today when a resident was lost in the corridor and asked me to help him find his room. All the bedroom doors and corridors look the same'* (Journal, 4 July 2015).

## 5.2 Longleaf: A typical Australian RACF

This section extends the description of the research setting provided in Chapter 4, to start to portray the lived world of Longleaf where the participants and for a time, I experienced being-in-the world-of-aged-care.

*'While I had analysed the drawings before visiting Casuarina House and understood the building to have a large floor plate with several wings necessary to accommodate 167 residents, I was unprepared for how homogeneously institutional the building looked and felt. It's quite depressing to imagine how it must feel to arrive as a resident or family member for the first time to be confronted by a large car park with two relatively undifferentiated entrances directly accessed from the car-turning circle. Incongruently, it seemed the service deliveries, ambulance pick-up, and resident drop-off area and entry doors were shared.'*

*My first memory of entering Casuarina House was that of stale air and the smell of strong cleaning products, as well as uncertainty about how to find Longleaf. I had to ask the receptionist to direct me as the amorphous foyer spaces of Casuarina House offered no clue to the location of Longleaf from the main entrance'* (Journal, 3 June 2015).

Despite the webpage for Aged Care Inc. describing their *'building stock as warm and homelike'*, I found Casuarina House, and specifically, Longleaf was dispiritingly more institutional than expected. The fear of falls and infection had created a task-oriented environment in relation to both care and building design, and the building looked and felt like a hospital.

The vinyl, easy to clean floors, minimal furniture, and the layout arranged to maximise circulation space and facilitate the ease of staff being able to move residents bore little relationship to recognisable living spaces. While these features assisted staff in their place of work, Longleaf was the abode of the residents. Balancing the conflicting needs of the different user-groups is undeniably challenging, but the building design seemed to have been more carefully considered regarding supporting staff to deliver care.

The interior colour scheme was generally neutral, typical of many contemporary RACFs and hospitals using cream, pale yellow, and white. The interior design of Longleaf appeared to be more about appealing to the desires of the family, than to the needs of people with dementia as discussed in Chapter 3. While the interior of Longleaf was perceived more positively by family as *'better than some of the other darker places we looked at'* (Paula, Greg's wife, impromptu conversation (IC), 30 August 2015), staff felt that the Longleaf should be *'More colourful. The colour, it's a bit institutionalised — sort of beigey. No colour...No brightness, like there's some artworks up on the wall, but they're quite insipid'* (Donna, staff- physiotherapist, PC, 24 June 2015).

There was little difference in the materials, furnishings, and wall colours used in the dining room, the bedrooms, and the corridors. Both the dining room and bedrooms had light-coloured timber-look vinyl flooring which was coved to form the skirtings, and the corridors had a pale green carpet with a blue pattern. Except for the bedrooms, the wall colour throughout the building was pale yellow with white painted doors and door trim. The corridors and dining room had white and pale-yellow dado panelling and white skirtings. The bedrooms walls were a pale beige colour, with white doors and frames.

The lack of colour contrast identified by Calkins (2009) and Marquardt et al. (2014) as essential for enabling resident orientation and way-finding was lacking, and the few mobile residents in Longleaf were rarely able to find their bedrooms. In addition to the neutral colour scheme, there were also few other cues such as wall colour or flooring material changes to assist residents in orienting themselves within the environment.

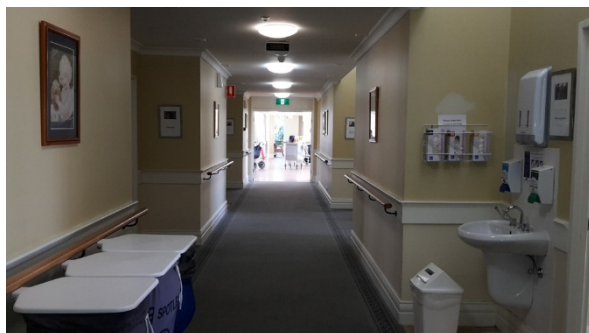


Figure 5.2 Corridors were painted the same and relatively indistinguishable.

A resident spoke about how he tried to use cues in the corridor to find his room, *'See this hand-basin. See this rubbish bin. It is near my room'* (Joe, PC, 4 July 2015). *'I feel sad that a bin is his physical cue but more so that for the most part, Joe remains unsuccessful in finding his room. He frequently enters other rooms by mistake, distressing himself and the other resident'* (Journal, 4 July 2015).

Not only were the interior aesthetics unsupportive of people with dementia, but other sensory experiences also seemed not to have been given due consideration. While the inability of people with dementia to cope with noise and excessive stimulation was discussed in Chapters 2 and 3, I also found the noise uncomfortable at times. *'There is an incessant electronic beeping that I thought was an elevator until after some weeks; I realised that it was the residents' call buttons that beeped until they were attended. The dining room could be disconcertingly quiet for hours at a time while residents nodded off in their chairs, and at other times, it was filled with the clattering of noisy trolleys, staff calling each other, and crying, groaning, or shouting residents'* (Journal, 1 July 2015).

I was not the only one to find the sensory experience of Longleaf unpleasant at times. One resident spoke of her discomfort. *'In here [dining room], there is so much noise. Hospitals are always noisy. It smells like disinfectant all the time too. They use a lot here in the hospital, so it doesn't smell like wee'* (Antonia, resident, IC, 5 September 2015). Another resident told me *'it always smells like old farts and dirty socks in here. That's why I won't let anyone close my [bedroom] window. I would rather freeze'*.

While some families reported that Longleaf *'smelt better than most care homes'*, I found the air quite stifling, and the fresh air when I left the wing a welcome relief from the combination of bleach, sometimes urine, and over-boiled vegetables from previous meals. *'Ventilation seems generally poor especially in the dining room, and the stale cooking smells from lunch seem to linger all afternoon'* (Journal, 26 August 2015).

The dining room was a paradoxical space and the most criticised by the participants. It was eerily quiet on weekends and in the evenings, but in contrast, during weekday business hours, the room was a hive of activity, and inappropriately loud and overstimulating. This contrast must have been particularly challenging for people with dementia.

*'Many of the residents were immobile and sat all day in tub<sup>6</sup> chairs. The dining room could have up to 10 residents sitting around, usually just nodding off in their chairs, scattered separately around the room outside of mealtimes'* (Journal, 18 July 2015). As one staff member said, *'No matter what time I arrive, it always feels like the day is waiting to start, but it never starts. It looks like a great, big waiting room. Everyone is just waiting'* (Donna, staff-physiotherapist, PC, 6 September 2015). When I asked what they are waiting for, Donna hesitated and answered quietly, *'they are just waiting to die'*.



Figure 5.3 Dining room: The photograph was taken on a typical weekday outside of mealtimes

The place where they mostly waited was referred to as the dining room, but it seemed to me to be, where everything happened, yet nothing happened. *'The weekdays are busier than weekends with so many people coming in and out of the wing. Within a short observation period, the pharmacist delivered medications, a GP arrived to see a resident, pathology samples were collected, and the printer was serviced by the IT Department. Additionally, a medication, a cleaner, and a drinks trolley were wheeled through the dining room'* (Journal, 12 June 2015).

*'Again today, I noted multiple people coming in and out of the dining room; entering directly into what is effectively the residents' living room, but few people acknowledge the residents. Some families greet other residents; others seem to march through, studiously ignoring those in the dining room as they quickly make their way to their own relative's*

<sup>6</sup> Wheelchairs describe the standard wheelchairs that were used by a few residents who were independently mobile in the chair, although most required assistance. Tub chairs were considerably larger, similar to mobile day beds where residents could recline, and were for the very frail and immobile residents.



*room down the hall*' (Journal, 24 June 2015). *'Yah, it's in the middle of everything, and people walk straight into it. No one walks straight into your lounge-room'* (Ben, staff-CSE, PC, 26 June 2015).

Despite the number of people passing through the dining room, however, the residents were not involved and remained sitting mostly alone; separate from each other making it challenging to interact with each other.

Staff and family also reported that their relationships were affected. *'It's hard to have a good chat with mum, not just 'cause of the dementia. There are all the other conversations going on in the dining room, and mum gets distracted. She listens in.... sometimes she butts into other conversations... she never would have done that before, but it is a bit embarrassing'* (Kathy, Jean's daughter, PC, 20 September 2015).

Family to family relationships were also influenced by the lack of spatial variety. *'It's so hard to have a conversation in here because it's so busy all the time, and with the tables are so spread out, I haven't really met anyone else [other families] yet'* (Mel, Mary's daughter, IC, 28 July 2015).

Families perceived that the nurses' station, which ran almost the full width of the dining room, affected their ability to form relationships with staff. It was 1.3 metres high, constructed of dark brown timber panelling with a central door leading to the kitchen, the RNs' office, and clinical room. Family members also conveyed perplexity about the design of the structure. *'In the beginning, when I saw it for the first time, I thought it's a bit too, too big and too..., and that desk, it looked like a bar (laughed). Probably because it's brown. I don't know. It's like a kind of bar, and I can see the staff behind there. But I suppose they have to be separate, but it feels like a barrier'* (Liz, Joe's wife, PC, 20 August 2015).



Figure 5.4 Nurses' station: Reported by staff to be modelled on a hotel bar. The material is timber. The bar was 8 metres long and 1.3 m high. There is a central gate leading to the kitchen, RN office, and medication/ clinical room.

Another family member described the central 'gateway' through the 'big desk thing' to the kitchen and RNs' office as a 'high traffic area'. *'I find the bar...A bit... Yeah. A bit of a barrier, visually as well as physically...So if, you're trying to get into the RN and you've got trolleys coming in and out, and it's noisy. Well, it's a little bit unwelcoming too, because that often there's so many people there, you sort of sometimes get the feeling that you're being a bit of pest. I sort of feel like, Am I supposed to? [Go through the 'gate']. I never quite know what the rules are'* (Kathy, Jean's daughter, PC, 20 September 2015).

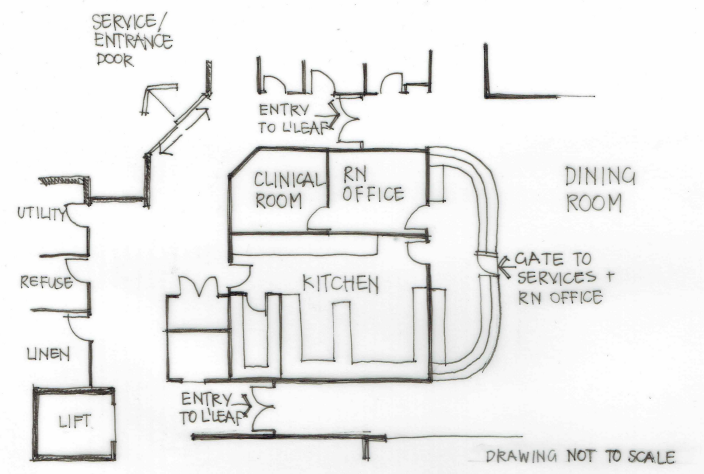


Figure 5.5 Floor plan of the nurses' station and service area. Families related that the gate was a high traffic area for trolleys and staff. They also felt that they were 'not allowed' to enter behind the gate to speak with the RN or make a cup of tea.

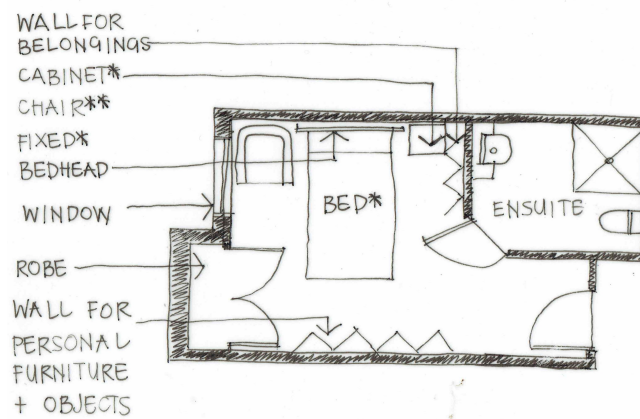
In addition to their criticism of the dining room, staff expressed concerns about the ensuite bathrooms. The bathrooms had identical floor plans and fixtures. The toilet seat, toilet, tiled walls, the hand-basin, vanity, and bench-tops were all white. The floor was pale grey vinyl with a coved vinyl skirting. *'Urgh, the bathrooms 'cause they feel cold, and they're white. They feel like a jail bathroom. They have a weird feeling to them. Like, put a colour in them. Yeah, 'cause they're just so white, and they're all the same and..... I don't know. They should have maybe shelves in the shower for them to put their stuff back, again making things... Feel like it's their bathroom and not somewhere, where they just take a shower and then leave kind of thing. It's so like a caravan park sort of place'* (Sally, staff-student nurse, PC, 6 July 2015). Family members spent less time and expressed fewer opinions than staff about the bathrooms but had strong opinions about the bedroom design.

The rooms were approximately twelve square metres, which is similar to an average-sized child's bedroom in a family home, and there was minimal flexibility to rearrange or personalise the rooms. The bedhead and cabinet were fixed to the wall. The window and small built-in robe took up the wall adjacent to the bed, and the other wall consisted of the door to the ensuite and the entry door.

One staff member described trying to see the bedrooms from the residents' point of view. *'I would want space that I could personalise my room to have pictures on the wall or a vase of flowers where I could look at them. At the moment, they're back here. I love flowers, and I can't see them when I'm stuck in bed. It's not a lot to ask. They're just some small things'* (Lyn, staff-OT, PC, 20 August 2015).

As a practising architect, I had also often thought while designing about the loss of personal belongings that must take place when someone moved from a house to a single room in the RACF. *'It must be to distil a lifetime of belongings and a household of personal objects into one room when people enter aged care. Now in Longleaf, I find it is not one room, it is effectively only one wall and one small wardrobe. The wall opposite the residents' bed where the TV is fixed is the only meaningful length of wall for personal furniture, pictures, and photographs, but I doubt if many of the residents could see the pictures'* (Journal, 24 June 2015).





DRAWING NOT TO SCALE

Figure 5.6 Bedroom floor plan: showing room layout and wall space for personalisation. \*Furniture provided by Aged Care Inc. \*\* The armchair was usually supplied by Aged Care Inc., and occasionally by the family.

Family members described the rooms as *'too small'*, and *'the rooms are impersonal, all the same'*. The aspect of the bedrooms that concerned one son most was the limited size that was *'not big enough to bring the things that are important. I think that's one of the traumatic things coming into these rooms and have to get rid of everything. See, they come in; they bring nothing here. The bed's here, the cupboard's here, TV's here. It's gotta be one of the big traumatic things is people downsizing that much, where they only have one tiny wardrobe to fit their life, their long, long life'*. He relayed that his mother had been a costume designer and *'her clothes were her life'*. *'And there was no choice of bed other than the bed supplied so that they can use the hospital linen here. Yeah, it looks like a hospital bed. Mum cried when she saw how small the wardrobe is'* (Brian, Elsa's son, PC, 25 July 2015).

Several staff recognised the limitations of the bedroom design for family comfort. *'The size of the residents' bedrooms does not allow for a big, comfortable chair or other chairs for family and visitors. I'd want to be able to have a chair of my choice in the room without... they've got a fixed bedside table to that backboard by the side, and then there's a tiny little spot for a chair that only this size of chair (points to small armchair) would fit in'* (Lyn, staff-OT, PC, 20 August 2015).

Each room had the same single pink or blue vinyl armchair, floral curtains, matching laminate bedhead and bedside cabinet. Similar to many RACFs, in Longleaf, there was an excessive use of vinyl flooring including in the residents' bedrooms, more characteristic of a hospital than a private bedroom, which is usually carpeted. *'I mean they are OK I suppose, but all the rooms are the same. They've all got the same curtains, all have the same bed linen, and they are not really personalised. Quite cold, quite clinical really'* (Donna, staff-physiotherapist, PC, 6 September 2015).

Thus, unlike the graduated and nuanced spaces of most buildings, notably the family home, there was effectively only two spatial experiences within Longleaf, the *'all or nothing'*, spaces of the very public dining room or the isolated bedroom, without a range of private, semiprivate, and public spaces found to contribute to resident well-being. There were no small lounges, niches, or threshold spaces where residents could feel less exposed, yet remain connected, able to observe others, and socialise if they chose.

Consequently, there were two spatial groups of residents: Bedroom Residents and Dining Room Residents. Bedroom Residents spent their days alone in their bedrooms where *'nothing'* happened, and where they were socially isolated. Bedroom Residents consisted of two sub-groups. The majority were those who staff determined needed to stay in their rooms such including those who were unwell, or in the final stages of life, discussed further in Chapter 7. Another small group of residents chose to be in their rooms often because of an expressed dislike for the dining room.

The Dining Room Residents spent the majority of the day in the dining room where *'everything'* happened although the activities rarely included the residents. Dining Room residents were immobile, physically, and cognitively frail. Some were in wheelchairs, but most were in tub chairs. The staff related that they were not in the dining room by choice but were brought out by each morning, often because they were a *'falls risk'* and required supervision.

The Dining Room Residents remained all day in the room where various people who were strangers to the residents entered their living space as I noted in my journal above. At mealtimes, tables were laid an hour before the meal served. Afterwards, the accoutrements were cleared, and the tables left bare. All the while, the residents mostly just sat with minimal interaction with others.

Thus, there were several issues with the design even though staff and family referred to Longleaf as *'one of the good ones'*. The most positive design aspects were that several bedrooms had views towards a lake and that the spaces were brighter than many of the other RACFs described by family and staff. When asked, several family and staff participants identified the deck as the best feature. It was not used very often, however, as it was hot and glary in summer, too cold in winter, and the heavy, hinged doors meant that the majority of residents could not access the deck independently.

*'This is one of the good ones'* however, usually followed the relating of criticism or disappointment about Longleaf. The disappointment may have been about how their frail mother missed lunch twice in a week because her room was isolated, and she was sometimes overlooked. It may have been about the lack of a family tearoom and quiet space. Families seemed to be reassuring themselves that their relative was in a suitable place. It may have been an acceptance that despite things not being as good as hoped, Longleaf was as good as it gets.

While family and staff often spoke directly about specific environmental features of Longleaf, residents rarely did. Their focus was on trying to understand their daily lives and lived experiences of being-in-the-world-of-aged-care, related through the following stories.

### 5.3 Ageing-in-place, co-location, and relocation

#### **Maree's Story: 'I'm not complaining. I just want to go home'.**

Maree had lived in an independent living unit (ILU) in The Village for several years prior to multiple relocations into various on-site RACFs for respite before finally being admitted to Longleaf. Her husband Angus continued to live in the unit and visited daily. At 85, Maree was one of the younger residents and the only resident in Longleaf able to walk without a frame. She was a small-framed, gentle, unimposing woman who was softly spoken and often confused.

Maree spent her days in her bedroom. She did not leave her room unless Angus accompanied her to the dining room. Maree spent her days in a semi-darkened room with the curtains pulled almost shut. Initially, it felt slightly odd to sit and converse in a darkened room, but she was always welcoming and gracious. All our conversations, including the prompted conversation, took place in Maree's bedroom.

Maree did not conceptualise Longleaf as a place of residence. In her understanding, Longleaf was a hospital, and she implied that when some nameless, unidentifiable event took place, she would be going home. *'I wasn't feeling at all sick or anything like that at home. How long do you think I'll be here'* (Maree, PC, 29 November 2015)? The notion of being in Longleaf temporarily until 'something happens' was a common thread in many conversations with residents.

Maree did not understand why she was living in Longleaf but, similar to many residents and family participants, seemed quite fearful about being seen to complain. She often repeated, *'I am not complaining, but I just want to go home'* (PC, 29 November 2015). *'Don't take this the wrong way but being here is just not the same as being at home but that's just my opinion'* (FC, 28 March 2015).

Angus found Maree's *'constant begging to go home'* distressing. Angus was a kindly man and devoted to his wife. He spent several hours a day with Maree but said that he dreaded arriving. The beginning of every visit was painfully the same, *"'I thought you weren't coming today'" followed by "when am I coming home?" This is always on her mind, 'cause she's not happy here ... in the situation, she's in, as far as I know'* (Angus, husband, PC, 28 November 2015).

He interpreted her plaintive and repetitive request to go home to mean that she was miserable, and he *'just wants her to be happy'* but *'now, no matter how hard I try, I just can't seem to get a smile out of her, and I think it's 'cause she's lonely'* Angus, husband, PC, 28 November 2015).

Maree's records indicated that before moving to Longleaf she *'had enjoyed an active social life and many friendships within The Village'*. However, her only visitor in Longleaf was her husband. The marketing material of Aged Care Inc. promoted the advantages of co-location as *'a village community where everyone is your friend'*. Longleaf, however, did not seem to be either socially or physically connected to The Village or beyond to the community or outside world.

Maree had not visited Longleaf prior to admission and had no understanding that Casuarina House, or any of the previous RACFs she had been admitted to for respite, were situated in The Village. Maree's world was mostly a dimmed bedroom in a place she did not understand and where she had little sense of time. She had been a resident for several months by the time of our prompted conversation, but when asked how long she had been staying, she answered, *'It would be a week or so wouldn't it? Very recently, I'm not sure. You lose track of the days, don't you? You don't know whether it's Monday or Friday'*, followed with a request to know how long it would be before she could go home (Maree, PC, 29 November 2015).

Angus spoke of how he tried to explain to Maree why she needed to stay in Longleaf. Similar to other family members he was careful not to imply that she now resided in the RACF permanently as he discerned that this would upset her. He shared that he felt guilty and experienced other complex emotions but was unable to take care of her in their unit. *'But it saddens me to think that I've got to have her in this nursing home situation. I got no other choice, not really, I just couldn't manage at home, especially at night, and she wasn't eating'* (Angus, husband, PC, 28 November 2015).

Angus worried that perhaps she did not leave her room because she found the place disturbing. *'I don't know what goes through her mind when I take her out to that big room because there's a lot of sad cases there, and that makes me feel...It's shocking. It's terrible. I don't know what's going through Maree's mind, whether this is making her feel..."I want to come home." Do you know what I mean'? He thinks that she stays in her room to avoid the dining room. 'They call it the dining room, but it's kind of not. That sort of throws me a bit, I think. [Chuckle] It's just not right. I think it's a bit higgledy-piggledy. And because of the nature of the patients too, you got people here in mobile beds or these.... tub chairs. They just sit all day, sleeping and being fed by the nurses. When I leave there every day, I think to myself; I wonder if those things are disturbing her'* (Angus, husband, PC, 28 November 2015).

When Maree was first admitted, she was observed to leave her bedroom on occasions but became quickly anxious, disoriented, and unable to find her way back to her room. *'Whenever I find Maree lost in the corridor, I have been attempting to help her identify landmarks or*

*cues along the corridor to help her find her way back. It's difficult as the doors are identical and there are few standout features. We talk about the hand-basin and a framed print with her favourite animal, a cat, just opposite her bedroom door'* (Journal, 15 September 2015).

Before our prompted conversation, I had assumed that Maree chose to stay in her room in response to her disorientation, as the physical environment did not support her ability to find her way back to her room. Following the first month or two after admission, I did not observe her leaving her room again unless with her husband.

As my understandings of lived experiences deepened and my research skills developed, I questioned my earlier interpretation of Maree's reluctance to leave her room due only to disorientation. While it seemed to partially explain Maree's anxiousness about leaving her room, it did not adequately make clear why Maree chose to keep her curtains closed and her door only open ajar. Perhaps this was an attempt to disassociate from the environment where she unable to understand where she was.

She was, however, somewhat more relaxed and at-ease when Angus visited. He also found comfort in *'Just being there. I'll sit alongside her a bit, and I might hold her hand watching the television. There isn't much conversation these days, but it's peaceful. But once that bond is there, you can't break it. I don't reckon'* (Angus, husband, PC, 28 November 2015). Angus said that he was not asking for much, *'all I want is her happiness, for her to be happy and to settle in'* (Angus, husband, DG 1 March 2016). At the time of the discussion group, Maree had been living in Longleaf for seven months.

It seemed unlikely that Maree would settle. As she repeated in every conversation with her husband and with me each day that she just wanted to go home.

Maree's experience was typical of many of the other residents in Longleaf with several relocations in and out of various RACFs within The Village before their permanent admission. For Maree, *'there is no place like home'*, and none of the previous RACFs had felt like home, but there was some comfort that *'I think at least, I'll be in this room for a while. I've moved too, too much'* (Maree, IC, 13 November 2015).

Maree did not seem to feel *'at-home'* in her room explained in part by the lack of personalisation and belongings from the family home, as well as what home may have meant for her. She did not understand where she was in the world beyond her experience of Longleaf as *'not home'*.

#### **5.4 Complexity and contradiction in 'all or nothing spaces'.**

##### **Marg's Story: 'My own little island'.**

Marg was 90 and had moved into Longleaf from an ILU in The Village two years prior to the prompted conversation. Marg was born in Belgium, worked previously as a Registered Nurse, and had four children and ten grandchildren. She was the only resident with a spouse residing in Longleaf although in a separate bedroom.

Marg was also the only resident that I spoke with who understood that she was in an RACF, mostly because she remembered being told rather than by recognising the environment. She felt that she had *'nowhere else to go'* and *'I would never leave Phil'*, her husband. Marg said that she had chosen Longleaf so that she could be with Phil, and *'I thought it was nice enough'* (Marg, IC, 15 September 2015).

During a phone conversation to seek consent for his mother's participation, Marg's son conveyed that she had no insight about the circumstances of her move into Longleaf and that her placement with her husband was by luck rather than choice. He provided a different version of his parents' dual admission. As this study was not intended to be factual, Marg's accounts were not challenged, and her understandings of her lived experiences valued in whatever way she chose to tell her story. It was her subjective experiences that provided meaning.

Similar to Maree, she did not understand that Longleaf was co-located within The Village and did not question why her friends did not visit. The design of the building made little reference to the location, which may in part have influenced Marg's inability to place herself geographically.

Marg did not perceive Longleaf to be in her home city, City X and said *'I stay down here because I know what it's like. If I go to City X, it could be much worse, you know'. 'Phil is comfortable here, and one nursing home is really like the other. They will be the same in City X, maybe worse'*. While three of her four children lived within half an hour of The Village, she thought that her children *'are all down in City X'* and seemed accepting that they did not visit as *'they live too far away'*.

While her husband lived in Longleaf, there was minimal interaction with Marg as he stayed in his room and she spent her days in the dining room. Phil had severe dementia, among several other ailments. Staff reported his cognitive and physical health as *'very poor'*. Phil died towards the end of my fieldwork.

Marg was the only resident who spent the days in the dining room by choice with both the cognitive capacity and mobility to spend more time in her bedroom. *'I can't do anything else, so I just sit out here instead. This is my life now. I can't read in here. I don't want to be in my room except to sleep'*. A sense of resignation often threaded through our conversations. *'It [the dining room] is a nice room, but there is not much going on. But what can they do anyway? What can they do in a room like that'* (Marg, PC, 5 October 2015)?

Marg sat on the edge of the over-sized dining room. *'I often see Marg watching, looking up every time staff or a visitor walked within the vicinity of her "island" hoping for a chat. She would be crestfallen when most often there was no friendly greeting, or any form of acknowledgement'* (Journal, 30 November 2015).

The potential for social connection seemed a possible reason for Marg choosing to be a Dining Room Resident. Marg knew few, if any, of the other residents and while she claimed that she could talk to anyone, she appeared to engage in very few conversations or interactions with staff or other residents.

Marg was the only resident to have appropriated a space within the dining room. Although she did not know where she was in the world, she had been able to appropriate *'my own little island'* within the RACF and at times, the sea of people in the dining room. All my conversations with Marg, including the prompted conversation, took place from her favourite chair in the dining room.

Marg expressed surprise that she had been able to find a space of her own and derived comfort from having a sense of choice and that others seemed to respect her place. *'They all know this is my spot, and they don't sit here'* (IC, 5 September 2015). *'This is my favourite spot. I was surprised no one else sat here, and I claimed it as my own (smiling). I don't want to sit at the dining table with the others. They don't talk anyway. I watch them, and all they do is sleep'* (PC, 5 October 2015).

While she perceived her *'island'* positively, her apparent hold on it was somewhat tenuous. As the dining room in Longleaf was the largest room in Casuarina House, it was used on occasions for

entertainment events that were somewhat at odds with the notion of a dining room and home'. *'All the furniture had been removed when I arrived today, and the dining room was almost empty except for a few residents in tub chairs positioned against one of the walls. As I watched, over one hundred chairs and several residents in wheel and tub chairs were lined up rows looking at a blank wall. Residents from the other wings in Casuarina House were wheeled in, and then we all waited for an hour for "something to happen"'* (Journal, 22 August 2015).

The event was a jazz saxophonist. While some residents appeared to enjoy the performance, others remained disengaged. Immediately following the concert, staff took the residents back to their wings and bedrooms, and the furniture replaced in the usual layout.

Clearly, the performance provided a meaningful activity for some residents and families, but many residents appeared not to engage or seemed to find the experience challenging. Several staff were not in favour of the concert or the perceived influence of these events on the design of the dining room. *'It's awful! It's like a school. Plonk them all in rows. I think it's important for people to see a concert or something but not make that the reason for having the ridiculously big area'* (Jan, staff-RN, PC, 28 August 2015). *'I think it's wrong that they just wheel in and then wheel out all these strangers. You can see from the residents' faces that they find the whole thing bewildering'* (Lyn, staff-OT, IC, 22 August 2015).

The room re-arrangement must have been particularly uncomfortable for Marg as the rows of residents directly faced her *'island'*. She went to her room, and once the concert started, she put her hands over her ears. I asked Marg if she would like her door closed to block out the music, but she anxiously responded, *'no, no, oh no, please I mustn't have the door shut'* (Marg, IC, 22 August 2015). It would seem that part of her enjoyment of her favourite position in the dining room was predicated on seeing and feeling that she had some form of connection to *'the world'*. Having the bedroom door closed, even though the noise disturbed her, may have further increased her sense of alienation.

Marg's ability to appropriate personal space seemed somewhat shaky, and it seemed likely that her ability to maintain the island that anchored her within the RACF would become increasingly more challenging as her cognition deteriorated because of her disease. I observed an occasion when another resident was sitting in her chair. Marg paced and seemed agitated. *'There is a man in my spot. Someone is sitting in my chair. Please, please, can someone make him move'* (IC, 24 July 2015)? After several minutes, the staff helped the other resident to find another place to sit.

A further unsettling and relatively foreign experience was Marg's witnessing of body removal after others died. *'I have been here two years now, and many people have died'* (PC, 5 October 2015). I noted an occasion that Marg was present and appeared distressed when the undertakers wheeled Richard's body through the dining room. Given the sensitivity of the topic, I did not discuss the experience with her any further. Chapter 7 tells the story of Richard's death but is mentioned here as another occasion where Marg's sense of her sanctuary within the dining room was compromised, in this instance by the conflicting needs of people living and dying in the one place.

Marg's days consisted of watching others. Watching was her main activity and source of connection to others. *'I sit here, and I just watch all day'* (IC, 20 January 2016). She repeated a similar phrase throughout our conversations. *'I sit here, and I have the same view every day. It never changes'* [resigned] (Marg, PC, 5 October 2015). She spent her day in the busy dining room where meals were served around the residents, staff and visitors frequently walked past her, and other residents were

exercised by occupational therapists, but the activities rarely directly involved Marg or the majority of the residents.

The dining room where *'not much happens'* accommodated many other people with different and complex needs and desires, where concerts were held, meals served and medication dispensed, where people worked and visited, and where residents spent their days waiting.

## 5.5 Making sense of place in Longleaf

### Jean's Story: 'I'm not a member here'.

Jean spent her days in the dining room, but not by choice. She was 93 and had been admitted to Longleaf in December 2014. She had worked in advertising and spoke fondly of how exciting it had been. She had liked being productive. She was clever and sharp, and I enjoyed her at-times surprising quick wit. Staff reported that she spent her days in the dining room because she was a falls risk. Each morning, she was assisted out of bed, dressed, wheeled out by staff, and positioned alone at one of the dining tables in approximately the same place each day.

Jean's husband and one of her two daughters had been dead for several years. Before admission, she had lived with her daughter, Kathy. Kathy visited daily and related that similar to other families; she usually timed her visits for mealtimes. *'It gives me a focal point, and I can actually do something. I can feed her. That way, I also know that she is eating'* (Kathy, daughter, PC, 30 August 2015).

Jean often spoke affectionately about her daughter. She recognised that her daughter helped her to maintain a sense of connection between herself and others. *'I have lost my memory lately. It's why I worry a bit. I don't want to lose everything. I need a connection, and Kathy is very good'* (Jean, PC, 4 October 2015). Another time, she said that it *'It is my daughter who keeps me connected to the world'*.

However, Jean did not seem to know where she was in the world. She spoke at various times of believing she was in the hospital, in a club or a guesthouse. She was generally fearful in the unplaceable environment and to protect her daughter, she sent her home in the afternoon *'cause it [Longleaf] turns into a brothel [nervous laugh]'* (Kathy, daughter, PC, 20 September 2015).

Her inability to place herself seemed a source of considerable distress demonstrated by a typical incident that I observed. *'Jean is sitting alone at one of the dining tables. She is visibly agitated, but nobody appears to be noticing so I sit with her. She remembered me and said that the distinctive heart-shaped necklace I wear helps her to remember me although she usually calls me Harry. A short time later when the meal was served, Jean became very agitated'*. She called out *'I am not a member anymore. Can I still eat? I am happy to pay for my meal'* (Journal and Jean, IC, 11 July 2015).

*'She opened the handbag that she always clutches in her lap. I have noticed that her handbag appears to provide her with some sense of security and normalcy. Jean checked to see if she can pay for her lunch, but she didn't have cash'* (Journal, 11 July 2015). She became increasingly distressed and cried, *'I've been robbed'*. Her daughter, Kathy, told me that her mother often thought that her money had been stolen. *'Mum thought she was robbed today as she went through her bag and couldn't find any cash. That generation felt secure with cash, but she is not allowed to have any in here. I left \$50 once, but the staff took it off her. It doesn't matter to me if it gets lost, but they are worried it causes problems. We live here, and we must abide by the rules, but it doesn't really make much sense if it upsets mum'* (Kathy, daughter, IC, 8 October 2015).

Over the course of the fieldwork, Jean frequently shared accounts of feeling excluded, and that her Catholic faith prevented her inclusion in *'the club'* because *'nobody likes Catholics in here'*. Her sense of feeling that she did not belong seemed particularly poignant when considering that the *'club'* Jean feels that she is not a member of is, in fact, her place of residence.

Jean rarely seemed at ease in the *'too public'* dining room except when her daughter was visiting. Her daughter related that Jean was so uncomfortable in the dining room that her previously non-violent mother had punched another resident for *'staring at me'*. *'They are always looking at me. Talking about me'* (Jean, IC, 18 August 2015).

Jean experienced isolation and feelings of not belonging each day. *'I arrived early at Longleaf this morning. It is strangely quiet as most of the residents are still in their rooms. Staff were not visible but likely to be assisting residents in their rooms. Only one resident was in the dining room. Surprisingly, Jean is still in her room. She is dressed, sitting in her wheelchair, and positioned rather unusually facing the wall near the bedroom door'*. Meg, the in-charge RN said that *'we have to orient Jean every morning. She never knows where she is, so we tell her she's at the Village hospital'* (Journal and Meg, staff-RN, IC, 3 September 2015).

Orienting Jean by telling her she is in a hospital adds to rather than alleviates Jean's confusion as she Jean did not know why she is in the hospital. She was at times, querulous and uncertain. *'I don't know why I am here. Can you tell me what the point is? People die in hospital'* (Jean, IC, 4 September 2015). *'I have never felt so directionless and lost in all my life. What am I supposed to do? Will someone tell me what is to be done'* (Jean, IC, 1 September 2015)?

A pattern that emerged in Jean's story, in observations and conversations with Jean was that her corporeal location within different spaces in the physical environment of Longleaf seemed to change her perception and her sense of which place she perceived herself to be. She expressed a sense of displacement and disconnection in both the dining room and her bedroom. In the former, she understood herself to be in a club to which she did not belong and in the latter, the hospital.

Despite being in Longleaf for almost a year, Jean expressed a sense of insecurity that may have been associated with being unable to place herself. Kathy said *'She gets confused. The thing that upsets her is, and I do this every day when I leave and explain to her that she's staying there tonight. And I even now say, when she says, "When can I come home?" I now say, "This is home, for the moment." And she'll want to see her room. She'll say, "But do I have a room?" And I go, "Yeah, room 15." And she said, "Where is it?" And so, I take her down and show her room, but it's like I'm showing it to her for the first time. But she's got this thing about... And then she wants to check with all the nurses, that they're aware'* (Kathy, daughter, PC, 20 September 2015).

*'Yeah, it's almost like she's frightened that she's going to be homeless for the night.... She becomes fraught every afternoon and is frightened and anxious'* (Kathy, daughter, IC, 27 September 2015). Kathy felt that *'the only thing that reassures her is when I show her her room. Then I show her her clothes'* (Kathy, daughter, PC 30 August 2015).

While showing Jean her clothes in her bedroom wardrobe helps to anchor her within the RACF, her room was generally not personalised. This is likely to have contributed to her disorientation upon awakening each morning and her belief that she was in the hospital. It is, however, a reasonable assumption that as her clothes support her to recognise her room each night, which suggests a more customised room with her personal belongings on display, may also benefit her well-being.

Her mother's inability to place herself is also challenging for Kathy. *'It's really hard. Mum doesn't know where she is. Because I didn't want to put her in a nursing home.... But somehow, we [families]*



*don't feel welcome here either. It should be just like visiting mum in her own home.... And I'll probably cry now, but...and she just seems miserable, and it's just not my mother'* (Kathy, daughter, PC 30 August 2015). The dining room was also uncomfortable for Kathy *'I'm sort of used to it the urine and bleach smell now. It's more the food smells. What I find the most difficult thing for me, they've [other resident's] all got varying degrees of awful eating habits and are so unwell-looking, and I can't eat there. I wish I could share a meal with mum, but I just can't'*.

Thus, the foreign hospital-like environment presented challenges for both Jean and her daughter. The aesthetic characteristic of the spaces in Longleaf was sterile, impersonal and clinical rather than relatable rooms that were comforting and familiar. It was unsurprising that Kathy felt unwelcome and that Jean, a woman with impaired cognition, perceived herself to be in the hospital when she woke up and looked around her stark bedroom. A hospital is often a place people rarely enter by choice, as well as being a place that we do not expect to stay indefinitely. It is a place associated with pain and illness, and where there are usually fewer expectations of feeling at home or belonging.

Jean did not know why she was in a foreign place, the hospital/ club /guesthouse, or have comfort in knowing that she will be returning to her familiar home. She expressed feeling lost and unsettled, unable to place herself and anguished that she does not know what to do to achieve her goals of feeling *'at-home'*, knowing where she is, what to do and to be.

## 5.6 Discussion

Explicit in the stories shared in this chapter was that the residents rarely understood where they were located in the physical world and seemed generally lost and anchorless in the world-of-being-in-aged-care. Similar to many institutional places of care, the residents were *'geographically detached from their former familiar physical environments and social networks that normally give meaning to people's lives and shapes who they are'* (Håkanson & Öhlén 2016, p. 48). All expressed a sense that they were somehow alienated or disconnected from familiar places and the world that they had previously experienced.

Other than physical proximity, there was no apparent connection between Longleaf and any of the other on-site RACFs or ILUs in The Village. There was also no connection between the other four wings in Casuarina House and Longleaf although all were within one building. For most residents, their physical world was contained within the walls of Longleaf and for many their world was only a small spatial segment the RACF, particularly the Bedroom Residents. Once admitted, residents rarely left the wing except for relocations to the hospital.

A generally assumed benefit of ageing-in-place and co-location was that the RACFs would feel connected to the retirement village and the move from an ILU into care less stressful due to familiarity. Not only were neither Maree nor Marg not visited by friends from The Village, they had not understood that Longleaf was situated in The Village, nor where the RACF was geographically located. Admission was experienced as separate from the outside world but also an entry into an unknown world of spaces unrelated to those of their previous experiences, especially the over-scaled, multi-purpose dining room.

The room that seemed the most negatively perceived by the families and residents was the dining room, although the staff expressed mixed feelings about the space. One CSE thought it was *'great to have one big room, makes supervision easier'* (Wayne, staff-CSE, PC, 24 July 2015). Others were more nuanced in their criticism, *'when a person [resident] is distressed; there is really no area which might be more calming to take them out of the dining room. They [the care staff] just dump people*

*all day in the big living areas because it maximises supervision, but there needs to be more choices'* (Donna, staff-physiotherapist, PC, 24 June 2015).

The views of the staff and family about the large public dining room generally supported findings by previous researchers including McIntyre and Harrison (2017) who found that whole rooms taken up by one activity, such as the concert discussed in Marg's story, and the lack of diversity of communal spaces negatively influenced choice and resident wellbeing. Jean's story illustrated that the multiple conversations and noise in the dining room was irritating, distracting, and did not support her ability to connect with her daughter. Jean's experience is similar to findings by other researchers that found that residents with dementia were less able to filter out useful information and focus on specific social interactions (Fleming et al. 2016) or understand behavioural expectations (Chaudhury et al. 2013) in large, not clearly purposed spaces in RACFs.

Prior to commencing this study, I had assumed that the residents in living spaces would have increased social interactions than those in their bedrooms. Ferdous and Moore (2015) found an increased likelihood of exchanges in places with high visibility and better accessibility or proximity but with lower levels of meaningful engagement. This was not the case in Longleaf, where few interactions took place, and residents were positioned apart in the dining room.

Marg's expressed main reasons for sitting in the dining room was to '*watch people*', but also likely in the hope of increasing her opportunity for social interaction. However, I saw very few people stop to speak or greet her as they passed through. The dining room at Longleaf was of a size that staff and other families could readily take a wide berth from residents and therefore few exchanges took place that may be more likely in smaller living spaces.

Further adding to the residents' spatial confusion resulting from their illness, was the multi-purpose use of the dining room, particularly activities that are unrelated to home such as medication dispensed from a trolley, physiotherapy sessions, and the concert, which was due to the lack of other spaces. The concert described in Marg's story, where the dining furniture was removed and chairs lined up in rows, created an experience that felt regimented and institutional rather than an intimate, social event more typical in a domestic setting.

Jean's experience of believing that she had to pay for her meal further evidenced Torrington's (2006) argument for spaces with unambiguous meaning rather than generalised spaces. A study by Chaudhury et al. (2013) specifically about dementia and dining rooms found a lower calorie intake, general confusion, and residents believing that they were required to pay for their food, as was the case with Jean. Distress also ensued when Jean and a few other residents realised that they were not going home after eating as would typically have been customary after lunch in a café or club, rather than the RACF.

While Marg was the only resident who understood that she was in a '*nursing home*', several residents including Maree thought that they were in the hospital, and others were simply unable to place themselves. Poignantly, hospital, club, and guesthouse, all the places where Jean feels that she was currently located, are transient spaces to recuperate rest or dine before returning home rather than comforting, secure places.

Jean sat in the dining room from just before breakfast until it was time for bed when she was wheeled from a space that felt like a club where she thought she did not belong, to another foreign space, her bedroom. In the home, our bedroom is often considered a place of retreat, but Jean believed she was in the hospital when she awoke disoriented each morning.

Jean spent her days '*feeling lost*' and '*directionless*', effectively unable to anchor herself in place. She was 'all at sea' in a place that was a misfit for her sense of identity as a productive and the '*cutting edge*' career woman that she had been, and the physical and social RACF environment. She felt alienated in a club where she was not a member and did not know what to do or how to be, calling plaintively, '*What am I supposed to do? Will someone tell me what is to be done?*'

There seemed little within the RACF environment to support Jean to form a place attachment, orient or recognise herself in the world-of-being-in-aged-care. Such was her lack of a sense of belonging that she fretted and had to ask if she had a room each night. It seemed that only by being shown her clothes in her room that she understood that she had a place to stay. She recognised that it was only her daughter who kept her '*connected to the world*' although she did not know where in the world she was situated.

Maree's only 'anchor' in the placeless world-of-being-in-aged-care was also a family member, her husband, Angus. She was isolated and lonely in her room but distressed by seeing the palliative residents in the dining room. Thus, Longleaf was a disturbing and incongruous place, where similar to Jean, she seemed to feel 'all at sea'. She was dislocated in both space where she could not place or orient herself in the environment, and in time believing she had only been admitted for '*a week or so*' instead of several months.

Her room was like her 'lifeboat' where she shut the world-of-being-in-aged-care out until it would be time to '*go home*' and leave the place she did not understand. In the meantime, she waited each day for her husband to visit. Angus visited daily but also struggled with the '*higgledy-piggledy*' environment, worried about Maree's experiences and felt guilty about having to leave her in a place where he understood that she was unhappy. The only anchor that both Maree and Angus had in Longleaf was each other.

Similar to Maree's experience, the presence of Marg's husband was also anchoring and somehow comforting for Marg even though they barely interacted. Having Phil live in the same RACF as she did seem to have provided Marg with a sense of belonging and autonomy, as she believed that she had chosen to live in Longleaf and had a purpose in looking out for her husband. She did not understand where Longleaf was located but seemed less distressed than Maree and Jean about her disconnection from the world.

Marg was one of the very few residents who were able to exert a small sense of autonomy and create a micro-territory, her '*little island*' where she anchored herself on the edge of the dining room. Her hold on her '*spot*' was somewhat fragile, and while she derived a sense of well-being through her sense of ownership of her '*island*', the organisation regularly exerted their ownership of the dining room transforming it at times, into an even more than usual alienating space for events such as the concert.

Her mobility, which facilitated her choice to spend her days in the dining room, also supported her to return to her bedroom during the concert. The majority of residents had little choice about which space they spent their day although Marg had only a choice of two. While she could leave the dining room where '*everything happened*', she was isolated and unsupported in her room to control the noise of the concert, fearful of losing connection to the world-of-being-in-aged-care.

Choice of spaces and residents' and families' opportunities to manage the way spaces could be adapted and used was lacking in the briefing notes which were discussed at the beginning of this chapter. The focus of the design notes was on the residents' physical needs and facilitating care tasks without reference to the subjective needs of the residents, their family, and staff. This was

instrumental in leading to the overall clinical feel and aesthetics that remains characteristic of typical RACFs, despite espoused theoretical notions of RACFs as home as discussed in Chapter 3. The qualities of the spatial experiences and design features analysed in relation to my pre-research expectations and observations of the world-of-being-in-aged-care proved to be far more institutional and alienating than I envisaged.

Maree's story demonstrated that the espoused advantage of co-location for continuity and connection with The Village and ageing-in-place was not evident and that she, like many other residents, was unable to place herself and consequently her primary goal was to '*go home*'. She stayed in her room to shut out the world-of-being-in-aged-care while she waited for Angus to arrive. Despite her ability to appropriate space, Marg did not understand either her current geographic or setting location. Her only anchors in the world-of-being-in-aged-care were her '*little island*' in the amorphous dining room and her non-verbal husband. Jean's story tells of profound grief and anxiety through feeling unsettled in a place where she could not situate herself, and which she understood as a place of temporariness, either the hospital or a club where she did not belong. Regardless of the inclusion of '*non-institutional*', '*homelike*' and '*hotel-like*' features, Longleaf did not feel like '*home*', and these three women did not understand where they were in the world.

While all the residents in the study shared accounts of feeling unsupported by the physical environment, the stories in Chapter 5 focussed on the experiences of the RACF as a place where they were unable to understand where they were or to feel in place. Throughout the stories above is a common thread of how the RACF environment did not enable the residents to place themselves or feel that they belonged in-the-world-of-being-in-aged-care.

The stories also illustrated their awareness of their need to connect in whatever way they could within the limitations of the physical environment the residents now found themselves in. There were few cues within the built environment to help them anchor themselves in place or connect with the RACF as their place of residence. Chapter 6 expands the notion of not belonging in place to focus on how the environment influenced residents' ability to understand who they were and how to be in the RACF.

## CHAPTER 6: CONNECTION WITH SELF AND THE WORLD

Chapter 6 extends the exploration in Chapter 5 of the influence of the physical environment on the residents' connection to place to include the phenomenological concepts less studied in RACFs, that of the residents' connection to self, others, and the 'world', a gap that was established in the background chapters which discussed the focus on evidence-based and empirical research.

Section 6.1 tells Joe's story of how the RACF environment influences his sense of freedom and connection to his self-identity. Section 6.2 relates May's story to illustrate the importance of personal belongings for supporting a sense of self and a sense of belonging within the RACF. Betty's story conveys her attempts to appropriate her own space and stay connected with the world in Section 6.3. Greg's story in Section 6.4 describes the sense of otherworldliness and inside and outsideness within the world-of-being-in-aged-care, while Section 6.5 provides an overview of my interpretations.

### 6.1 Enablement/disablement of the meaningfully familiar

#### Joe's Story: 'I am losing contact. I am incomplete'.

Joe was 92 and had lived in Longleaf for eighteen months at the time of our prompted conversation. Joe was a proud Dutchman who had lived an active and adventurous life that included being a WWII fighter pilot. He had made his fortune in manufacturing after migrating to Australia. He often spoke longingly of freedom and travel, and his beautiful home on the waterfront.

He considered himself a '*gentleman*', with '*proper manners*,' and liked to dress well. Despite his diagnosis, Joe demonstrated '*surprising insight*' into his condition, according to an RN when he spoke of '*being too dependent on Liz*' [his wife].

Throughout our many conversations, I learned much about his personal history and life philosophy. His level of confusion and ability to follow the thread of a conversation fluctuated. Joe worried that he was not always able to adequately articulate himself and stories of his lived experiences, '*I am, I get mixed up*' (PC, 11 September 2015).

Several residents, family, and staff reported that Joe called out '*help, help, help*' with increasing frequency during the last few months of my study. A staff member related that rarely were his calls because he needed assistance, '*it's not like he needs to go to the bathroom or anything*' (Wayne, staff-CSE, DG, 10 March 2015). Joe's plaintive calling seemed not to be about needing specific care. Rather, it was a plea for '*help, help*' from his suffering and grief.

Joe often spelled out his name or pointed to pictures and photographs of himself on the wall, '*this is Joe. I am up there alright*'. Perhaps it was his way of trying to maintain contact with himself, '*I am Joe E, that's who I am*'. Perhaps his habit of speaking in the first person was also to remind the staff and me of who he was. It may have been a long-term idiosyncrasy; it may be a result of his brain pathology. It was apparent, however, that he used the portraits, in particular, to help stay connected with his sense of past and self.

His expression of the loss of his past life, everything that was '*normal*', and of losing his sense of self, his connection to others, and his loss of hope and freedom was heartrendingly clear and conveyed throughout our conversations. '*I am sad; every day is a sad day. I am just not right*,' sometimes while crying (Joe, IC, 15 September 2015).

Part of Joe's sadness seemed to be his awareness that while it was Liz who helped him maintain his connection with himself, others, and the world but that this was now limited. They were located in

separate geographic locations, *'I could be happy too if my wife was here with me in this building'* (Joe, IC, 15 November 2015). Joe experienced the separation from his wife as a separation from himself, and his previous way of being-in-the-world.

Similar to many of the residents, his connection to others, primarily his wife, was key to his sense of well-being. Liz was the person he most closely related to, *'We had so much in common'*, and *'We were a team. We are the same'*. His wife was aware that as she was Joe's only meaningful social connection and that she was his conduit to connect with his previous life. *'I have to be here for Joe. He tells me "it makes my day," so I keep coming because I know that. I know he needs me'* (Liz, wife, DG, 12 March 2016).

Threaded through all our conversations were notions of the loss of the familiar, *'I don't do what is normal in here,'* and his sense of his loss of *'freedom'*, a term he frequently used when describing grieving for his past life, colouring his lived experiences in Longleaf.

Joe often talked about his life as a fighter pilot and of his travels. Themes of freedom and movement featured heavily in his stories of flying, driving fast cars and motorbikes, and late in his life, caravan travel with Liz. Freedom seemed to be a key aspect of Joe's sense of self-identification. Significantly, while Joe's demeanour was often subdued, he became animated when he talked about flying, making hand movements to demonstrate loops, or when he used the pictures on the wall to speak of his past adventures.

Joe spoke in some detail about the meaning of his personal belongings in his room. He regularly took cues from the objects, mostly paintings and framed photographs of his previous home, planes, travel, and wartime experiences to remind himself of his earlier adventurous life and sense of self. When I asked about his lived experiences in Longleaf, he became sad and answered *'Well, this is very minor (waved his hand around the room). Before, you know. I was, I am, I did a lot of actions, actions, like I flew different types of planes like the Tiger Moth, the Harvard 2B plane and the Spitfire...but now.... nee<sup>7</sup>, this is not my place at all'* (Joe, PC, 11 September 2015).

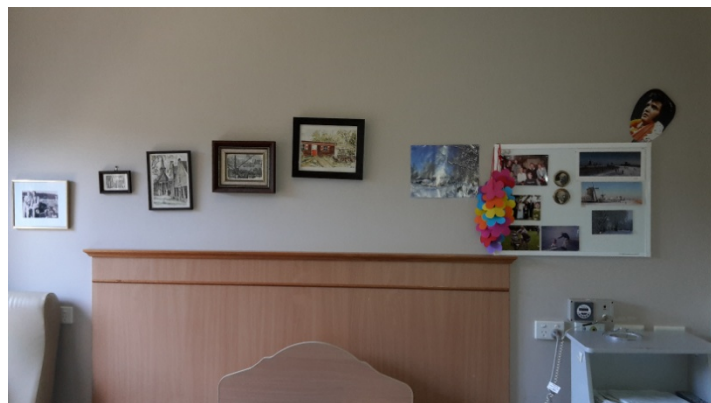


Figure 6.1 Joe's personal belongings: Left photograph- One of Joe's favourite items. It was a portrait of Joe as a young fighter pilot. Right photograph- Framed drawings and photographs of some of his previous homes including his childhood home in The Netherlands.

Liz reported that she had brought objects to *'help him feel it was his own room.... I thought these were his favourite places and times, reminders of his good life'*. His favourite object seemed to be a

<sup>7</sup> Joe had been born and lived in Holland until the 1950s. Translation: Nee-no.

painted portrait of when he was a fighter pilot during WWII, *'I liked freedom, ja<sup>8</sup>, ja, ja. I felt free when I flew'* (Joe, PC, 11 September 2015).

Joe often reminisced and spoke about freedom when he told me about his previous home and his travels with his wife, *'I don't like it here. My house in X Street, I felt freedom. I could see who I wanted, we could watch the boats, we could sit and do what we wanted, or we could go out'* (Joe, FC, 22 March 2016). He often spoke symbolically of not feeling that he was part of the *'team'* anymore, which he associated with his loss of freedom and connection to himself and his wife. *'We were a team. It was about freedom. Liz and I are the same; without her I am incomplete'* (Joe, PC, 11 September 2015).

Joe spoke of his growing despondency. *'I know that the staff are concerned that I am depressed, but that is just how it is for me now. I have no hope'* (IC, 15 January 2016). He related that he had expected to *'go home and things will be normal again'* but realised toward the end of the study that he did not have the freedom to choose. *'I was hoping but now I know I will never be allowed out of here'* (Joe, IC, 21 January 2016).

Unlike his previously active life, he spent most of his days alone in his room, and the only thing he looked forward to were visits by Liz. Joe frequently became wistful as he reflected on his past and was quite sad about where he perceived his current life to be. *'It was a profoundly sad moment when he spoke explicitly about freedom and action, then looked around his room and tears rolled down his face'* (Journal, 15 January 2016).

At times, he made unfavourable comparisons between the physical environment and aesthetics of his home and Longleaf, *'We had quality bricks, this chair, all vinyl...I would never have vinyl. At home, we had chairs covered in...in plush. In here, the look, it is cold. My home is so much more beautiful'*. It seemed, however, that the buildings were a metaphor for himself, and he was speaking of the contrast between how he had perceived himself as *'a quality man'* and his current sense of self, *'but this....[waving his arm around the room], I am not as good as I should be'* (Joe, PC, 11 September 2015).

Small and seemingly unimportant aspects of the physical environment and ways of being encapsulated symbolic messages of not *'feeling welcome'* or *'at-homeness'* for Joe. He was particularly distressed by drinks served *'in plastic cups with no saucer'*, and *'fake timber [laminated] built-in furniture'* which were the opposite of his previous *'quality'* home and to him symbolised the poor quality of the RACF and why he did not feel *'at-home'*.

Joe also expressed the move from his family home as a loss of his meaningful everyday activities. He spoke of missing things that were important to him and what he commonly described as his *'normal life'*. He missed *'my chance of looking well-dressed'* and his *'normal'* bedtime at ten or eleven pm. *'Here, we go to bed at seven or eight, and I can't sleep. Here everything is controlled'* (Joe, IC, 30 August 2015).

Joe was the only resident that I spoke with who was able to express a sense of grief and identify the loss of a specific physical home, and how it had represented freedom. For him, the experience of admission into Longleaf was a *'double detachment'* similar to that described by Schillmeier and Heinlein (2009). Not only had he been relocated to a building that bore little physical resemblance to his previous home, but he had also lost his sense of feeling at home through established through

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<sup>8</sup> Ja-yes.

meaningful and comforting everyday practices and routines such as his preferred bedtime and rituals.

Familiar daily activities give a point of reference and meaning to our lives. For Joe, the self-identified *'man of quality and freedom'*, the loss of personal routines and small, daily pleasures, and the little things such as *'making proper coffee from a machine'* and *'my chance at shaving well and being quality dressed'* were experienced as more than a loss of a sense of *'at-homeness'* (Joe, IC, 15 November 2015). It was also about his sense of who he had been in the world.

The loss of his previous home and separation from Liz represented the loss of freedom, adventure, and movement that Joe appeared to grieve for most profoundly and that he identified as a loss of *'contact'* with himself. *'I don't like my life. Nee, but I am unhappy with my life because I live here, and this is not my home. This is nothing like my home, and I miss my wife. I miss freedom'* (IC, 5 September 2015).

The move from the family home into Longleaf had involved many losses for Joe; not the least of which was the sense of losing connection with himself and what had been his *'normal'*. His losses were at once about the loss of his aesthetically pleasing physical home, a place he also strongly identified with his sense of self as a man of freedom and *'quality'*.

## 6.2 Belonging and belongings

**May's Story: 'It is, but it isn't my home now. It's where I belong. I just have to accept it'.**

May was 92 and had been admitted five months before our prompted conversation. She grew up, went to school, and lived most of her life in a suburb close to Longleaf. She had two daughters and six grandchildren. May was proud of *'her bit for the war effort'* when she had made gas caps for the soldiers and was a talented dressmaker. She spoke of finding comfort in her faith in God. Her records listed her most significant achievements as her children and travel, and that she loved Christmas and lunching out. Our conversations were natural as she spoke freely, often with relatively long, and at times, repetitious monologues with minimal prompting.

May thought that she was in hospital although she did not understand why. *'I don't have anything wrong with me. I'm just old'* (IC, 6 September 2015). She became sadder as time passed, *'I realise now that I won't ever be leaving hospital. I'm not ever going home'* (May, IC, 10 October 2015). She missed many aspects of *'being-at-home'* and her previous *'normal'* life. According to her daughter Kate, her mother was *'desperately lonely'*. May accepted that while her husband could visit, she believed that *'he can't stay with me because I am in hospital now and it's not allowed'* (IC, 10 October 2015).

I was often inspired by May's resilience and efforts to *'accept things'* and to *'make the best of things'*. She recognised that remaining positive was challenging, *'if only people really knew how worked up I can be. I just want to go home, but I don't cry anymore'* (IC, 4 September 2015). May opened the prompted conversation with *'Nowhere is perfect to start off with. You know, you've got to come here, and that's it and accept it as it is. Yes, accept it. This is home'* (PC, 17 October 2015). She repeatedly said *'that there is no point in grizzling'* and that acceptance made her life, and that of her family and the staff easier.

*'It is but it isn't my home, it's where I belong now, and I have to accept it'*. Given the repetition, there were times when I wondered who May was trying to convince that she belonged in Longleaf, herself, or me.



It must have been challenging to leave her previous home of 76 years, which had been the centre of the activities that had given her life meaning and provided her sense of who she was. May often spoke of her sense of self as a *'productive woman'*. *'I love cooking, and I always did. I miss cooking. I miss everything. I used to make a lot of cake and chocolate leaves, using gardenia leaves. I had gardenias in my garden, and I grew vegetables and flowers. I gardened every day and had a special seat to drink my coffee. I loved cooking. I really did. I used to make nine fruit cakes for all the family. This is the first year I didn't [said sadly]. That was my pleasure, but I don't have that anymore, and I am no use to anyone'* (PC, 17 October 2015).

Despite grieving for the family home, May was the only resident who referred to her room as *'home'*. While she frequently repeated the need for *'acceptance'*, *'finding the positive'* and that *'this is home now'* she appeared to have been coached by her daughter. Her daughter was well-intended, and May did seem to find some comfort in calling her room *'home'*.

In part, her sense of belonging may be accounted for by her perception that she stayed in her room by choice. It may also be that she felt ownership of her room through her daughter's efforts to make the room feel *'a bit like her own home'* (Kate, daughter, IC, 21 August 2015). May *'chose'* to be a Bedroom Resident although there was considerable ambiguity around the notion of whether she preferred to be alone in her bedroom rather than in the company of others or because she felt unwelcome and unsettled in the dining room.

An alternative interpretation of the reason May did not leave her room include her lack of understanding of the layout of the wing despite her five-month stay. Similar to the majority of Longleaf residents, she inhabited and was familiar with only minimal spatial areas of the wing. *'She hasn't yet worked out it is a u-shape.... And the little wing on the other side of the dining room doesn't even exist in mum's mind...Except for her room and possibly the dining room, the rest of the wing is totally foreign to her'* (Kate, daughter, PC, 30 August 2015).

Kate worried that her mother was lonely and isolated in her room, but shared that May was distressed by other unwell people in the dining room. She described that *'they seem to have two very different types of people in there. You've got what I call palliative care, and a week or two ago, I think there were eight or nine residents in their chairs, drooling and just staring at the ceiling ... 'But actually, from mum's point, it really quite distresses her that she is ....to see someone suffering like that'* (Kate, daughter, PC, 30 August 2015).

Kate and several other family members had indicated the need to include at least two living spaces, one for the more *'able'* and another for the more *'unwell'* or *'palliative'* residents. She felt her mother would be more likely to enjoy a space where she *'felt more like the others'* and *'had more in common with them and would be more likely to spend less time alone in her room'* (Kate, daughter, PC, 30 August 2015).

While the majority of Longleaf residents felt that they had little control over who entered their room, May often described a sense of comfort and empowerment that she derived from feeling that she had some exclusionary capacity. *'You have got to accept that this is a hospital and not a house. But you make your room your home, so I don't invite everybody'* (PC, 17 March 2015). May spoke quite extensively about being able to choose who came into her room, and it was clearly of personal significance and seemed to be an aspect that promoted a sense of her room belonging to her. *'If they are not too funny, I say, come and sit down for few minutes...but I am a bit choosy. It's my home and just because my front door is open, doesn't mean you wander in'*.

Reflecting afterwards *'I found it curious that May was never observed to close her door, a symbolic gesture often associated with creating a boundary between home and outside, and a mechanism for choosing who enters. During our prompted conversation, however, staff entered her room four times without knocking'* (Journal, 17 October 2015).

May's room was one of the more pleasing, primarily because it was one of the most personalised in Longleaf and had a view of the water. Her daughter was the only participant who spoke explicitly of trying to create a link to her mother's previous home and her sense of self. She regularly provided fresh flowers, significant for May who had loved gardening and *'of course; they come from mum's garden'*. The hand-knitted rug was May's knee rug that she had used when watching TV, and she had brought it in to help her *'feel more at home'*. Kate had knitted a matching bow for the door to help May identify her room as her home. The belongings that she selected were a deliberate attempt *'to try and bring some reality into her. Um, normal telephone, little table, and her clothes just help her recognise.... I don't know that this is her home now'* (Kate, daughter, PC, 30 August 2015). Kate said that she would like to have done more to make her mother's room more relatable to her previous home but felt that the rules limited her.

Personalisation was supported in principle by staff, and several said, *'residents seem to really like it when families put a few decorations up'* (Sally, staff-student nurse, PC, 6 July 2015). However, Kate reported that *'there was a leaflet that said you can't put anything on the walls without asking. I was lucky that that picture frame hook was there, so I could find a picture frame that took one hook. As for anything else, we are not allowed to touch the walls'* (Kate, daughter, PC, 30 August 2015).

Kate described some additional items such as her mother's framed tapestries that she would like to have hung, *'as a reminder of who she was'*, but felt constrained by organisational policy. Her interpretation that specific belongings served as a reminder of May's achievements and sense of self was reasonable.

It was clear that May's belongings, particularly her wedding photograph, were a significant source of connection and cued many conversations. May spoke with pride of how she had *'made my own wedding dress, hand stitched all the lace'* that then led on to conversations about her work as a seamstress. She explained why her husband was wearing a uniform in the photograph, which then extended to sharing her family life history. While this study confirmed findings by Rubinstein (1987) and Chaudhury, H (2008) of the importance of personal objects to remember the self, I also found the photographs provided cues and memory prompts that supported residents to connect with others and to participate in the research.

Kate did her best to help keep her mother connected with the world within the limits of what she knew and felt she was *'allowed'* to do. However, she perceived that admission to the RACF meant that her mother had to sacrifice *'the things she had around her all her life'* noting that her parents had *'lived in the same house since they were married'* (Kate, daughter, PC, 30 August 2015).

Despite the apparent comfort that many residents seemed to derive from the presence of belongings, the majority of residents had few, if any, personal effects. *'Of the forty rooms, twelve have been personalised to a varying extent. Most of the personalisation was relatively simple, a few photographs on the wall or bedside cabinet, sometimes a few paintings and ornaments from home'* (Journal, 11 September 2015).

For May, tapestry and cooking had been a significant part of her life and identity, but the rules in Longleaf did not allow her to decorate her room, hang her tapestries, cook, or *'even make my own sandwich'*.

Despite being one *'of the lucky ones'* with an attentive daughter, May misses her previous *'normal'* life and stays in her room. Longleaf did not include a kitchen or a garden to support her sense of self as a *'useful'* person. May expressed finding the world-of-being-in-aged-care outside her room foreign and challenging, with little understanding of the layout of Longleaf and her understanding that the other residents distressingly unwell and unlike her. She seemed only to feel a sense of belonging by staying in her room, *'her home now'*.

It was likely that the efforts her daughter had made to *'bring a little bit of home in here'* significantly assisted May's sense of acceptance that she *'belonged'* in Longleaf and that her bedroom belonged to her.

Qualities of *'at-homeness'* that are often associated with family, shared memories and familiarity are undeniably challenging to achieve in the typical RACF, but it was apparent that Kate's conscious efforts to *'bring a bit of Mum'* into Longleaf had been beneficial.

### 6.3 Feeling or not feeling *'at-homeness'*.

#### **Betty's story: 'I sit here because it means you don't feel so alienated'.**

Betty was aged 88 and had resided in Longleaf for almost three months at the time of our prompted conversation. Betty had been a well-connected and gregarious woman. Her records indicated that she had enjoyed a considerable social life including establishing an over 50s singles club. She often spoke of soirees and luncheons she had hosted of which she seemed to be particularly proud. The staff reported that she had a son, but he rarely visited. Betty told me that her granddaughter, of whom she was very fond, visited regularly but I did not meet her.

Betty spoke with a beautiful, lilting voice and seemed quite eloquent but a few minutes into our first conversation, her confusion became apparent. Each visit commenced with a re-introduction of myself followed by an almost identical conversation. Betty was often repetitive, and while the range of conversation topics was limited, she was always charming and entertaining. In every conversation with me, Betty spoke about feeling displaced and wanting to go home and her attempts to remain connected to the outside world, especially to nature. She also repeatedly explained why she chose to sleep in her chair rather than her bed, suggesting the significance of her choice.

Betty was a Bedroom Resident. Her spatial experience was different to most residents as she not only spent all day sitting in her chair and gazing out her bedroom window but also slept in her chair every night.

I never observed visitors or staff with Betty and sitting alone in her room seemed a complete contrast to the socially active woman that she had been previously. The environment did not seem to support the outgoing person that she had been before her admission. Although she had some mobility, I did not observe her leaving her room. Betty chose to stay in her room, in part, because she did not feel at home in the dining room *'because it's not a refreshing place, not out there. It's not really my kind of um...place'* (Betty, PC, 29 November 2015).

I often found Betty waiting to be collected by someone and taken somewhere. She would have put on a dress, done her hair up, applied lipstick, and checked her handbag contents in readiness for her *'outing'*. Several times, she thought she was going for surgery, at other times to the hairdresser or the dentist, sometimes the theatre or out to a luncheon, but I was unaware of her leaving Longleaf.

She did not, however, seem to understand she was in the RACF, nor did she know the name or location of Longleaf. Rather, she spoke of *'this place'* as if Longleaf was another temporary stop on the way to the place that she wanted to be, which was *'home'*.

Betty described feeling unsettled and spoke of experiences of time and location displacement. A sense of being dislocated threaded through her stories. She did not know how long she had been staying in Longleaf, *'Good grief, no more than a few weeks I shouldn't think'*, and did not understand how she came to be admitted or how long she was to stay in Longleaf.

She was upset by several relocations before her admission. *'Something happened at home. I don't know what. And then, the ambulance came and took me off to the hospital, and that's how I landed from one hospital to another, to another. At the moment, I'm no nearer getting home. So, I'm not too happy'* (Betty, PC, 29 November 2015). Betty seemed unable to comprehend a series of pre-admission relocations or feel that she had any choice or control, *'You just go from one to the other. I mean, they say, "Oh, you're only here just to assess you, just for a few days, and you'll be going home at the end of it." But you don't, at the end of it, you go to another place. And that's how you go on; every place you go to, it's the same thing. And still, I don't go home'* (Betty, PC, 29 November 2015).

For Betty, her *'beautiful home, all white walls with lovely, colourful art'* had been the centre of her life and connection to others. She had hosted many *'lovely events'* in her home. *'I mean, I used to give a lot of luncheons. I had a large dining room table, and we'd extend out to the garden terrace at the back, and sometimes I had twelve to sixteen people to lunch'*, in stark contrast to her reduced social connections in Longleaf. Betty believed her many friends did not visit because *'my friends at the moment won't know how to find out where I am'*.

There were aspects of the physical environment and objects within that did not seem to support Betty's ability to place herself. *'I don't like the bathrooms. Well, it's not terrible, but there's loads of machinery in them. It is most odd'*. Betty was particularly puzzled by the *'white equipment'* in the small niche space directly opposite her room. The niche seemed a remnant space rather than a purposefully designed lounge. It was oddly located, with no natural light and unusable as a sitting room as staff utilised it for storage of various lifters, slings, and wheelchairs.



Figure 6.2 Sitting niche across from Betty's room: Singer sewing machine and sofa that were inaccessible due to the storage of lifters and assistive equipment.

Betty seemed most offended by the old sewing machine in the niche space. *'It's funny because there's a Singer sewing machine there that is exactly like one I used to have years ago, at home. I thought, my god there's a Singer sewing machine. It's just stuck there. It isn't used by anyone for sitting. Because it really was sort of a lounge in there. It was really, a sort of...meant to be something else, isn't it'* (Betty, PC, 29 November 2015)? While the inclusion of the sewing machine was well intended, for Betty, it seemed the incongruous placement was disconcerting and unsettling, and further evidence for Betty that Longleaf was not *'home'*.

Her belief that her stay in Longleaf was temporary had several implications. While the benefit of belongings was discussed in May's story above, it is interesting to note that individual meaning-making and ways of being to do with personal belongings varied more than expected before commencing this study. Betty's response was one such unexpected finding. While her own home was reportedly well appointed and she loved art, there were few personal objects or art in her bedroom except a statue of an elephant and a photograph of her dogs. Betty joked, *'I think they're trying to encourage me. [Chuckle] You know, to appreciate the centre'*. When her granddaughter had asked if she wanted more, *'I said, "No, don't do that. I don't know how long I will be here". Because if they bring in more things, it might mean I am staying here, and really, I just want to go home'* (Betty, PC, 29 November 2015).

Betty's choice to remain in her chair seemed to afford significant meaning as was apparent in its recurrence as a central thread in every conversation. There seemed a multi-level symbolism and a number of interpretations of the stories she told. In the world-of-being-in-aged care where she felt she had been involuntarily placed, choosing, and at times it seemed fighting, for her preference to *'stay'* in her chair seems to give her some small but important sense of control in an otherwise foreign environment. *'They all think I am crazy, you know, but...I have big arguments about the chair. Everyone wants me to go on the bed, to go in the bed. I much prefer to sit here in this chair'* (PC, 29 November 2015).

While Betty did not appear to socialise with the staff and residents, staying visually connected with others remained significant, and she spoke about her fear of further disconnection from others if she lay on the bed. *'It's just like...I don't like to be isolated, made to sit on the bed where I don't see anybody and I don't hear anything, and I get really cheesed off.... I watch the weather changing, but yes, I can see that side [pointing to the corridor] as well. It means you don't quite feel quite so, you know....um alienated'*.

There seemed several fears layered into Betty's choice to stay in her chair. During the day, she could look out the window, but this did not explain why she also spent the night in her chair. A possible interpretation was revealed in her anxious telling of experiences concerning the development of her disability. *'I went to bed and just woke up one morning and couldn't use my right hand, not then, not ever again properly'*. And then another morning, *'I got out of bed, looked in the mirror, and screamed. My whole face had sagged'*. Betty's notes indicated that she suffered from Bells' Palsy, and I wondered if part of her reluctance about going to bed was a fear of waking up with a further diminishment of her physical capabilities. Sitting in the chair also suggests she is and will be ready to leave and go home at a moment's notice.

Home as discussed in Chapter 3, is often understood as a person's territory as well as being where they feel that they belong. For Betty, however, Longleaf lacked many of the qualities commonly associated with feeling at home. She seemed to experience little sense of 'ownership' of her room except for her corner.

While not expressed explicitly as fear, it was apparent that Betty felt anxious in Longleaf and unsafe. Bachelard and Jolas (1994) argued that home is a haven and our corner of the world, but for Betty, it seemed that her loss of self and diminished cognitive capacity meant that the sanctuary she was able to secure was only a corner in her room. By spending her days and nights in a chair, it was as if Betty had created a space that she felt capable of controlling. It seemed to afford her some sense of security and continuity in an environment experienced as both placeless and alienating. To this end, she had arranged magazines and newspapers and had a few personal belongings on the windowsill.

For Betty, Longleaf was experienced as a foreign place and similar to other residents, she described herself in a placeless space that as her illness progressed, heightened her sense of alienation. She was the only resident who explicitly used the word *'alienating'*, but she was not the only resident who sensed themselves to be in a non-place, a place that remained nameless, and unidentifiable. Betty was not able to identify Longleaf beyond it being *'not home'*. The simple act of not being able to call a place *'home'* can be considered unsettling itself. For Betty, not only was Longleaf *'not home'*, it was a placeless environment.

For the most part, however, Betty presented as uncertain, disoriented, and unable to understand where she was. She described her isolation and separateness from the world. *'It's a funny place here. Like I am on this, this little isle but I don't know what this is all about, it does feel most peculiar'* (Betty, PC, 29 November 2015). Betty appeared to be struggling to understand being-in-the-world-of-aged-care but had done what she could to stay connected with the world by appropriating a small space in the RACF, similar to Marg's story in Chapter 5. For both women, their *'isle'* seemed an attempt to anchor themselves with the RACF environment and to maintain some sense of autonomy.

Staying in her chair was not solely about her efforts to feel in control. Betty spoke extensively about the pleasure she derived from her place by the window *'Well, I am happy here'*. Her position also seemed to be her main source of connection *'to the lovely world out there'*. She often shared accounts of which birds she had seen, the flowering of the gumtree blossoms and changes in the weather. *'Earlier on, I thought that's rain, and I looked up, and it was, how wonderful. I love rain; it reminds me of my childhood and times with my father. Some of those childhood memories, they live with you forever, don't they'* (Betty, PC, 28 March 2016)?

Betty recounted experiencing a sense of connection to her past and her identity through connection to nature. Even a seemingly minor connection with nature, such as a view to trees or a lake seemed to provide some benefit and satisfaction. Her connection to nature, as limited as it was, by a view from one position, afforded her a sense of connection with the *'world'* beyond the walls of Longleaf.

Betty's story illustrated that her view of the natural world afforded several benefits. Watching nature from her *'isle'* provided a meaningful, familiar activity, a connection to fond memories of her past, and a connection to the world beyond the walls of her room.

It seemed that Betty's focus and source of well-being were holding onto some sense of connection to the outside world and a hope that she was *'going home soon'*. She seemed to elicit some comfort from the personal control of the small personal space that she had managed to create within an environment that felt otherwise alien and placeless. However, towards the end of the study, I felt she was starting to lose hope about *'going home'* and that she had somehow been abandoned. *'At one stage I was ready to just quit the whole place and go home, but maybe if I died here that would be more convenient than having me home in my own house'* (Betty, PC, 28 March 2016).

#### 6.4 Inside-ness and outside-ness

##### **Greg's Story: 'Nobody understands. It's a whole other world in here'.**

At 73, Greg was the youngest resident in Longleaf. He had a diagnosis of Parkinson's disease with Lewy Bodies Dementia. Greg had been the director of an accounting company and had loved to study, fly small planes, garden, and make models. He had led an active, outdoor life of travel, marathon running, and cycling. Although Greg used a wheelchair, he was inclined to get up and try to walk. As he was considered a falls risk, staff wheeled him out to spend his days in the Dining Room, although it was not his expressed choice.

I did not observe any interaction with other residents, but he was visited daily by his wife, and frequently by his four adult children. His wife, Paula said *'we have worked out a little roster to make sure he has someone come every day, otherwise he gets very distressed. Even when we miss one day, the next day he seems to find it even harder to remember us, and he seems to almost ignore us, like we are strangers'* (Paula, wife, IC, 15 August 2015).

Paula was engaging, articulate and often spoke of *'trying to stay positive and make the best of things for Greg's sake'* (Paula, wife, IC, 15 August 2015). She had cared for Greg for years at home until his care needs had become more than she was able to manage but had found placement brought complex emotions and new challenges. *'I cried in the nurses' office every night for the first three months'* (Paula, wife, IC, 15 July 2015).

Paula related that she held out for the more cognitive but unpredictable moments when Greg was responsive and engaged. She worried that she might miss a *'good moment'* if she did not visit daily. *'The staff said not to come every day, to have some life outside. But what can you do? It is hard for me, but even harder for him. I can't remember my life before this all happened'* (Paula, wife, IC, 15 July 2015). *'I don't want to miss one of his good moments. I know I can't be here 24 hours a day, but his good times are so random and becoming rarer, and I might miss them'* (Paula, wife, PC, 15 August 2015).

Of all the prompted conversations, the conversation with Greg was one of the most challenging, initially close to being ceased when he started to become distressed. Fortunately, Paula was present, and together we were able to reassure him. The conversation was one of the most poignant and illustrative of the sense of loss and disconnection with others and the world that is the lived experience of being-in-the-world-of-aged-care.

Initially, Greg interpreted my questions to mean he was permanently admitted to Longleaf. Greg, *'Well, I well, I don't actually live here, don't you know, want to be here. Are you saying I live here? I don't really. I don't live here!'* Paula: *'He doesn't want it to be implied that he is here for good because he doesn't want to be here'*. Greg: *'I want to be with the family. But I don't want to be here for long, or at all, ever really'* (Greg and Paula, PC, 9 October 2015)!

Despite his diminished cognitive and communication capacity, Greg's symbolic language throughout our conversations clearly expressed his sense of ill ease and disconnection from others, and the world illustrated by this excerpt. Greg: *'I just don't exist anymore. I am not a part of it.'* Paula: *'When you go out, do you like it because you are not inside anymore?'* Greg: *'Yes, I am not a part of it. That's the problem. It's not like before, that's right. Christmas is coming'*. Paula: *'Do you feel like you are not a part of outside anymore?'* Greg: *'In a way. Yes, not a part of anything. Christmas Day. Christmas. I want my fair share. I want my fair share of it'*. Greg seems to be aware that he is speaking metaphorically. *'Err, it's not about Christmas. I want my fair share. I've got a wife, and I don't want anything else. It's about that sort of thing'* (Greg and Paula, PC, 9 October 2015).

Greg did not know where he was in the world, either metaphorically or physically. At the time of our prompted conversation, Greg had resided in Longleaf for nine months but tells me that *'I just want to be with my wife, but I have been stuck here now for two and a half years'* (Greg, PC, 9 October 2015). Greg expressed his experience of disconnection to time and the length of his admission somewhat symbolically.

The reality of being in the RACF was uncomfortable for both Greg and his family, and they did not openly refer to his admission as permanent or Longleaf as an RACF. *'Well, we don't talk about that. We just say, "You're here..." , because he came in as a respite situation, and he'd been in the rehab,*

*but he had to go to another place that could help him more because he couldn't go to the place where he'd been previously, because that was too hard for them. So we came here, so we haven't ever [stressed] discussed it. We just say, "You're here because at the moment you need two people to look after you". We just talk like that. Because I myself like to, I think... oh, well, it makes us feel better as well actually' [small laugh] (Paula, wife, PC, 15 September 2015).*

As protective mechanisms, families often employed euphemisms, *'we say he is in rehab just to go with what he's thinking. Now you just be in that moment with them as much as you can, making them feel comfortable, isn't it really? But gosh, it wears you out' (Paula, wife, PC, 15 September 2015).*

Greg was one of the more fortunate residents in Longleaf with an engaged family who regularly took him on outings. Paula often spoke of how they worked consciously to help Greg maintain a connection with his previous life. *'He was an outdoorsy man. So we say let's go to the park and sit under a tree. He thinks that's a park over there, so that's what we say, "Well, let's go to the park. It's nice to be able to do that. You don't want to always be in this falseness of air, do you? It's nice to try to include him in family activities' (Chuckie). We say, "Oh, we want him to take notice of his surroundings. Look at the trees. Look at the animals. Look at the ants" (Paula, wife, PC, 15 September 2015).*

The *'park'* that Paula referred to was a remnant of land bounded by three roads and a building. It was not physically connected nor was it considered a part of Longleaf or designed for family and resident use. Rather, it was a grassy area and the land uneven and difficult for wheelchair access. However, the *'park'* was earmarked by Aged Care Inc, for a future Independent Living Unit development.

Paula shared her understanding of the reason other families visited infrequently or not at all. She believed that visiting the RACF, even The Village café, was too confronting. *'I suppose because it's all in your face and you feel sort of threatened or something. Not threatened, but confronted' (Paula, wife, IC, 19 October 2015).* Paula implied that people avoid confronting their mortality. Paula's friends did not visit because *'They wanted to be thinking of something else. But this is my situation. Going down there [The Village café] takes me away a little bit or Greg away a little bit from here. It's like normal life, so it's quite nice' (Paula, wife, PC, 15 September 2015).*

*'Normal life'* was a key aspiration expressed by several families, residents, and staff members. Paula described the dining room environment as challenging because it was too noisy with many distractions. Despite the perceived disabling quality of the environment, Paula is, however, occasionally able to connect with other family members in the dining room. *'If I have a bit of a laugh with Mel [Mary's daughter] or Liz [Joe's wife], I feel much better when I go home, that I've had that little bit of lightness. So, it's nice to be able to sit together. I think it does make a huge difference if you have a little rapport' (Paula, wife, PC, 15 September 2015).*

Greg did not enjoy the dining room although it was where he spent his day. He worried that his family did not like it. *'The young ones, the kids...they don't; they don't like it'. 'This is actually a girl's room [the dining room]'. He felt out of place, perhaps because most of the staff were women. 'It seems to be, you know...The nurses, you know. Only for the girls. The girls can be noisy'. 'It is a busy place. Yes. Nothing happens at all, but it's noisy — nothing in the room' [with resignation] (Greg, PC, 8 October 2015).*

*'It's quite difficult for some. I just sleep'.* When I asked how the design could be improved, Greg answered, *'If I could ask a question, I guess. It would be some sort of experience, especially for the*



*family. The only thing that concerns me is, would be my wife, to make sure she's got everything she needs. I don't consider anything else'* (Greg, PC, 8 October 2015).

Greg seemed only to feel at ease when his family is present. *'That's the best time'*. For the most part, he was unhappy and often agitated. He tells me plaintively, *'I am still here. No one seems to know I don't want to be. I just want my wife'* (Greg, PC, 8 October 2015).

At the time of our prompted conversation, the presence, or lack of Greg's personal belongings mattered less than it did for others as he only slept in his room at night. In contrast to other family members who reported not knowing what belongings were helpful or permitted, Paula had made a conscious decision not to bring objects from home.

*'We've brought nothing, and I can't quite cope with that yet. I don't want to be sort of bringing home here. It is so funny. I know a lot of them have... like they've got their little bits.'* Paula's coping mechanisms was to keep the RACF and home separate. She expressed not feeling ready to accept Longleaf as Greg's place of residence. *'And then some of it is that you've seen those things at home, and you can't... I know I sound stupid, and it would be good for Greg, but I can't quite come to the feeling. Maybe as time goes by, and he is in his room more, but I can't, I haven't accepted it, not very well... But I don't want to have those things from home and associate them with the nursing home'* (Paula, wife, PC, 15 September 2015).

Paradoxically, while Paula spoke of needing to detach home from the RACF, she also related feeling isolated and in *'another world'*, and *'that it's a whole other world in here. Nobody else understands'* (Paula, wife, IC, 19 October 2015).

*'I never expected to be in this world. I live in a whole other world now'. 'Even when I go home, go outside, I worry constantly about what is happening inside, in this world. It's my world now, too'.* The notion that the RACF becomes the families' *'world'* and that their needs were important did not seem to have been considered in the design of Longleaf. Not only was Greg unhappy, his family especially his children seemed quite uncomfortable in the dining room environment. They spent little time in the dining room and, instead, chose to take their father out.

Being-in-the-world-of-aged-care was experienced by many as a fragmentation of the family, in particular, in spousal relationships. Greg expressed the separation from his wife as his primary source of suffering, and it was a cause of considerable distress for Paula. Greg and Paula both expressed profound grief for the loss of their several decade-long identity as a couple and their dreams of a shared retirement.

Their separation as a result of Greg's placement was physical, emotional, social, and psychological described through their stories as a series of complex experiences of grief, losses, and disconnections over time as the disease progresses. The separation was made further complex as Greg's ability to connect fluctuated and was unpredictable. Paula feared to miss his rapidly decreasing *'good moments'* when Greg was *'more himself'* but also felt *'unwelcome'* and uncertain in the world-of-being-in-aged-care.

Paula recognised the importance of hers and the children's role in assisting Greg to remain connected despite their own problematic experiences of Longleaf as an alienating environment. While Greg's family was committed to visiting and supporting his connection to self and others, the environment of Longleaf was not experienced as welcoming, especially the dining room where Greg spent his days when his family was not present.

Similar to the recommendations of other families, Paula said the children would feel *'far more comfortable visiting if there was a small lounge room so we could take dad out of the dining room, which stresses them out'*. The need for Greg and his family to *'feel welcome'* in the Dining Room became significantly more important when he was transferred into a tub chair towards the end of my time in Longleaf as this curtailed their ability to take him on outings.

For Greg, however, all that mattered was Paula. *'All I care about is my wife. I don't want anything else'* (Greg, PC, 9 October 2015).

## 6.5 Discussion

Both residents and family members reported the experience of Longleaf as alienating and *'a whole different world'* where participants felt uncertain about their behaviours and expectations of ways of being, and who they were in the world-of-being-in-aged-care, which was not supportive of their lived experiences.

Being immersed in the world-of-being-in-aged-care meant that I also experienced, albeit in a comparatively limited way, some of the sense of *'otherworldliness'* of Longleaf. While the different activity levels between the working weekdays and the evenings and weekends affecting what Edvardsson et al. (2012), identified as the *'atmosphere'* was described in Chapter 5, the contrast of the *'feel'* of the environment between day and night was even more dramatic.

Staff had recommended that I spend time at night and in the very early mornings for an authentic and comprehensive understanding of being-in-the world-of-aged-care. *'It's a completely different world again at night in here, a madhouse, really. Nobody else has any idea'* (Meg, staff-RN, IC, 15 July 2015).

It was indeed an eerie experience, and I cannot imagine what meaning people with dementia make of the night world in the RACF. *'The wing is darkened except for the nurses' office and a few dimmed lights in the corridors. The sense of 'otherworldliness' of Longleaf is further highlighted at night and quite haunting. There is screaming, there is the sound of residents quarrelling, and I can hear more than one person sobbing. The sounds are dislocated, and I can see shadowy outlines of unidentifiable people in the corridor. I reflect that I am both cognitively capable and here by choice. The residents, however, are unable to leave' and are bound by their illness and care needs to stay in an unplaceable and alienating environment'* (Journal, 18 September 2015).

The spaces of the RACF were also fraught during the day with ambiguity of experiences of *'insider'* and *'outsider'* status. Families and residents related many instances of behavioural expectations that were unclear, and which challenged their sense of self within the RACF. While residents such as Greg and Joe spoke of the *'best part of the day'* as when their families visited, families seemed quite shaken by both the physical and social environment of Longleaf.

May, Greg, and Joe's families spoke about the dining room as if it was the only living space in Longleaf although there were two additional smaller living spaces identified by staff as available for family use. One had been appropriated for storage of equipment as we saw in Betty's story and the other, the Activities Room, was believed by the family members to be unavailable, or they were unaware that it existed.

Several family members and residents thought that the Activities Room *'belonged'* to the Recreation Officer for organised activities or generally belonged to the staff, *'because when I come down, staff are sitting here and the doors are shut'* (Liz, Joe's wife, DG, 12 March 2016). While Kate was a

successful professional in the outside business world, in Longleaf she was uncertain, *'I don't know if it's allowed or not, to go in there [Activities Room], even on weekends when nobody is here'* (Kate, May's daughter, PC, 30 August 2015). The doors of the activity room were usually shut, understood by families to mean that they were excluded.



Figure 6.3 Activities Room entrance: The door was often closed, and the lights turned off. Families related believing that the room 'belonged' to the Recreation Officer and that it was for use by staff to take their breaks.

Doors represented a significant narrative. While doors offered one of the few physical mechanisms for family and residents to create a sense of privacy and their 'own space' within Longleaf, I rarely observed bedroom doors to be closed. Families and residents related that while not explicitly instructed to keep doors open, they seemed to lack confidence to make choices they would readily make in other environments. *'Nobody else ever shuts the door, so maybe it's not OK'* (Liz, Joe's wife, DG 2, 12 March 2016) and *'staff might need to come in or be able to keep an eye out, I don't know'* (Bernie, Tom's wife, IC, 15 November 2015). Previously taken-for-granted practices, such as the choice to shut a door, became symbolic of the bedroom belonging to the organisation and thus the residents and family are *'outsiders'*, while they are *'inside'* the world-of-being-in-aged-care.

The language used by Greg and Paula was similar to that used by the majority of the participants. Longleaf or the world-of-being-in-aged-care was constructed as *'inside'* separated from the rest of the world, which was constructed as *'outside'*. *'In here', 'out there', 'out in the world'*. These are not terms commonly associated with feelings of connectedness and belonging. Instead they speak about displacement and alienation (Hertzberg & Ekman 2000). Within Longleaf, there were varied and multi-levelled meanings apparent around the notions of inside and outside worlds, and clouded boundaries and meanings of inside-ness and outside-ness.

It seemed a particular blurring of assumed dichotomies of inside-ness and outside-ness when families expressed experience of Longleaf as an inside space in contrast to the outside world, while simultaneously relating experiences of being an *'outsider'* within the walls of the RACF. While Wiles (2005) theorises that places do not exist in isolation, but are always connected to other places, Longleaf felt like it was in a vacuum. The lack of physical connections such as paths to other buildings in The Village including the café at The Banksia Centre seemed based on the assumption that people with dementia did not need to feel connected.

Phenomenologists propose the human need for connection extends beyond the connection to the self and others to include 'the universe and nature' (Healey-Ogden & Austin 2011, p. 2(1); Sarvimäki 2006). At a practical level, considerable time spent outdoors had been part of many residents' everyday lives and identity, a therapeutic, taken-for-granted experience of who they were in the world (Kuosa et al. 2015). For Greg, who had spent much of his life in nature, the move into the *'artificial'* world of Longleaf, with little connection to outdoor spaces seemed to be experienced as a displacement from the *'active, outdoorsy man'* he had been, but the design of Longleaf did not include a garden, and the deck was not designed for independent access. Being kept in the

alienating dining room also seemed to add to his sense of disconnection from the world, and he did not understand where he was, or where Longleaf was although it was in his childhood suburb.



Figure 6.4 Left Photograph-Deck Exterior. The deck looks over the Independent living units to the lake in the mid-distance. Right photograph-Deck from Interior. This photograph shows the heavy hinged doors that the majority of residents were unable to open independently. The curtains to the light well on the side of the dining room were permanently closed.

Not knowing with certainty where they were, left residents with little reference to their previous life, what to do, or who they were any more, an issue flagged by Örvulv (2010). The uncertainty I observed may partly have been due to the pathology of dementia but also because the residents were in a situation that was difficult for them to handle and interpret. Joe, who had always felt in control of his own life, was both unable to understand or regain his lost sense of *'freedom'*. Betty's life had previously revolved around her social life that was no longer available or possible. It seemed that all she had left was her ability to choose to sleep in her chair and her *'fight'* to stay connected with her sense of herself through her view to nature and watching those who walked past her room to reduce her sense of alienation.

Many of the links to residents' previous lives had been forfeited on admission. The *'little things'* was a phrase used by residents, staff, and family on many occasions in the study. It seemed that previously taken-for-granted normative practices of home had taken on significant meaning through loss. It had been the *'little things'* that had seemed to have helped residents such as Joe to *'feel complete'* in their previous homes, but there was little consideration within the design such as a family or resident kitchen to support continuity of home practices. The loss of little things, such as making a sandwich for May, *'real coffee'* for Joe, and the ability to make a hot drink when Betty felt like it was perceived by the residents as *'not normal'*.

There can be a practical necessity for serving drinks with meals and scheduled trolley rounds to ensure adequate hydration essential for well-being. However, what appears to be lost for the residents was the ability to choose to make drinks at times outside organisational routines. Rasmussen and Edvardsson (2007) found that it was the *'little things'* that promoted *'being me,'* connecting people to their previous everyday life, habits, and routines. Similarly, participants also spoke of the *'little things'*, and despite their dementia, residents in this study were able to recall their previous everyday rituals and experiences. Joe and Mays' stories illustrate the grief resulting from the loss of personal everyday rituals that had previously given meaning to their lives. The lack of enabling to recreate some of their practices and routines within Longleaf added to their sense of disconnection and inability to their sense of connection with the self.

'Who we are and feel able to be can change from place to place' (Malpas 1999, p. 173). Joe's perception of the *'poor quality'* of the physical RACF environment was incongruous with his sense of self as a man of *'quality'*, and Greg refused to identify with the environment, preferring to believe he was in a transient space.

While May strove to maintain some sense of autonomy through her control of who entered her room, she was otherwise unsupported by the RACF environment to retain her previous sense of identity as a *'productive woman'* and expressed feeling *'useless'*. Interestingly, her sense of her room as *'home'* was through territorial control, while her daughter focussed on recreating *'home'* and helping her mother to feel she belonged and maintain a connection to her sense of self with physical objects and belongings.

Personal belongings may foster a sense that residents can manage the process of adjusting to the RACF lifeworld thereby feeling a sense of belonging and security (McDonald 2011). There was no evidence in the briefing documents that personalisation had been considered in the design of Longleaf, and the limited wall hanging space and size of the rooms meant that there was little that family and residents could do to shape or modify their space to *'make it more their own'*. While McDonnell (2009) theorises that homogenising spaces exacerbates people's sense of loss of individuality and self-identity, the residents in this study rarely spoke directly or explicitly about the environment; rather they focussed on their experiences within the environment.

Familiar objects and ways of being in an environment can convey symbolic meanings of everyday life when living in a nursing home (Edvardsson et al. 2008). The loss of objects and ways of being for residents seemed to symbolise a loss of self and what had been comfortably familiar. While previously found in studies on mid-stage dementia, it was shown here to remain important for those with late-stage dementia.

May's daughter's judiciously selected personal belongings had assisted her mother to feel more *'at-home'* and connected with the RACF. However, while belongings are often assumed universally beneficial within the RACF, Betty did not want her belongings as she interpreted it to mean that she was not *'going home'*. Joe's portraits both supported him to remember his past, but also saddened him when he made unfavourable contrasts between his previous life and his situation in Longleaf. Greg and his family did not want to associate objects from home in the RACF.

All of the residents in Chapter 6 expressed experiencing Longleaf as a place of temporariness. While May conveyed some acceptance that she now lived in a hospital, usually interpreted as a place of temporariness, Betty and Joe did not. When both Joe and Betty realised that they were not returning to the family home, both become more despondent, increasingly less connected to self and distressed by their sense displacement and a lack of being *'at-home'* described by as a similar experience as homelessness (Dovey 1985). These experiences are particularly poignant when considering the RACF was likely to be their final place of residence.

In studies that focussed explicitly on *'at-homeness'*, the feeling of being metaphorically *'at-home'* was directly associated with subjective well-being (Rasmussen et al. 2000; Schillmeier & Heinlein 2009). *'At-homeness'* was found to be a contextually related meaning of wellness that could potentially be strived for despite illness through a sense of belonging or feeling in place, as discussed in Chapter 3 but lacking in Longleaf even for some residents with theoretically supportive personal belongings.

There was little within the built environment that supported their diminishing capacity to connect with their sense of identity, with others, and with the world. Joe and Mays, and less directly, Greg's stories reinforce Kitwood's identification that people with dementia need both a supportive environment and others to help them maintain a sense of connection with the self. Further, the stories contradict common assumptions that residents are unaware of their losses or their dependency on others to maintain connection to the self.

Families' lack of '*feeling welcome*' in the wing also threaded through the stories. '*Feeling unwelcome*' is significant. Not only do residents rely on families for their connection to themselves, families wish to spend time in the wing which in the final stages of their relatives' life often under particularly stressful conditions. Neither group, however, felt supported to feel like themselves, or how to be which was particularly poignant for people with dementia.

The loss of the '*little things*', such as the rituals of making a pot of tea or coffee, took on considerable significance for the residents. The loss of normalcy for both families and residents, described as the activities and comforting practices of home, seems less supported in larger RACFs such as Longleaf than smaller domestic scaled 'best-practice' design models described in Chapter 3.

'Normal' life meant different things for different residents. For Joe, admission to Longleaf had meant the loss of his previous '*freedom*' to choose whom he spent time with and what time he went to bed. 'Normal' also meant '*being themselves*'. For May, this was being a '*productive woman*', for Joe, being a man of '*freedom*'. While Betty had been a socially active woman, Greg had been an '*outdoorsy*' adventurer, but there was little within the environment of Longleaf that supported a sense of continuity with who they had been.

Betty did her best to create some sense of territory within the otherwise alien place by attempting to control her small corner within an otherwise strange world. For both Betty and Greg, two of the few residents with a connection to nature, limited as it was, some comfort was derived within a place that was otherwise unsettling, but for the most part, residents were unsupported by the environment to maintain a connection with their sense of self.

The sense conveyed in this chapter was that of Longleaf as a whole '*other world*', isolated, separate and unlike the known '*outside world*' and previous familiar lives and sense of self, with negative effects on the resident, family, and staff everyday lived experiences. The residents' and families spoke of displacement, feeling unsettled, and unable to anchor themselves in place. The need for connection was expressed as paramount but, the alienating RACF environment was shown to be unsupportive. Chapter 7 extends the discussion of the need for normalcy and especially for connection when people are their most vulnerable, that is during the residents' final days of life.

## CHAPTER 7: DEMENTIA AND DYING IN 'ANOTHER WORLD'

This final interpretation chapter intends to extend the discussions about the lack of cues and support within the physical RACF environment for people to place themselves, or to connect with the self, others, and the world during one of our most profound stages of life, that of dying and death. While all the stories relate to experiences of late-stage dementia, this chapter focuses more explicitly on the participants' experiences of death and dying.

Chapter 7 includes stories told through the voices of four residents and their families. Antonia's story in Section 7.1 illustrates the complexity of caring for the living and dying in one space and her awareness of the death of other residents and her pending mortality. Section 7.2 presents Mel's story about mother, Mary's death in hospital, while Tom's story in section 7.3 is about his final days and expectation of death in Longleaf. Richard's story in Section 7.4 conveys the distress, particularly for residents and family, due to the apparent lack of consideration of Longleaf as a place to support the dying. The chapter concludes in Section 7.5 with a discussion about the stories.

### 7.1 Living in the waiting room/ Dying in the Dining Room

#### **Antonia's Story: 'Please don't leave me. I won't be around much longer'.**

Antonia was 87 and had lived in Longleaf for almost two years at the time of her prompted conversation. Her foot was amputated, and she was confined to a tub chair where she had been for '*a thousand years*'. Antonia had lived an interesting life of travel, artistic pursuits, and activism before a '*sudden and shocking*' admission to Longleaf following a stroke and a fall. She was a tiny, bird-like woman, barely able to see over the edge of her chair, with little resemblance to the photographs in her room of the large, robust woman dressed in brightly coloured clothes.

Antonia had been a dancer on the stage in London before immigrating to Australia. She chose Antonia, her stage name, as her preferred name for this study. Her interests were '*politics, reading, music and anything to do with the arts*'.

Her daughter, Denise, described Antonia as a '*social butterfly*' who '*went out every day even if she was a bit unwell*' and who '*just loved clothes and colour*'. Denise related that her mother had been '*larger than life. It's quite sad to see her like this now*' (Denise, Antonia's daughter, prompted conversation (PC), 6 September 2015).

Antonia was a Dining Room resident but was frequently anxious, crying, calling out, and clinging onto people if they attempted to leave her. She was frequently repetitive, and at times, the conversations were fragmented and confused. Her language was often symbolic, but the message was often one of fear and alienation.

Denise lived an hour from The Village and spent a block of four or five hours most weekends in Longleaf, and co-ordinated with her siblings so that several visited together. '*While the environment [in Longleaf] is nothing like her old home, we try to make it feel a bit more like mum's old world. She always loved a good get together*' (Denise, daughter, PC, 6 September 2015).

Antonia's family grouped chairs and shared food and drinks, newspapers and playing cards that they had brought in. '*I tell mum, she's lucky she had lots of kids, and I've noticed that we seem more comfortable here than others*' (Denise, daughter, PC, 6 September 2015). As a group, they were able to appropriate a space within the large room. Interestingly, larger families were the only visitors I observed who appeared to be moderately comfortable and able to make a part of the dining room temporarily their own.



Throughout our conversations, Antonia related several conspiracy-type theories. Denise, a psychologist, offered qualified insights into her mother's stories. *'Mum thinks they [the staff] are all out to get her. So, she's got a bit of psychosis, a paranoia. To me, it's very normal for her situation. Some people might say that it's some brain damage, but I would actually see it as a psychological reaction. She's trying to make sense of her world. And her old world was so different from this world, and this just laying around watching people, she's frustrated and frightened'* (Denise, daughter, PC, 6 September 2015).

The most challenging aspect of visiting for Denise was accepting that Longleaf was the most appropriate place for her mother, as regardless of the quality of care she knew her mother was unhappy and frightened. *'Like I walk in, and she starts with her crocodile tears, as I call them. 'Cause it's... I think she is just trying to express how unhappy she is. I mean, I think she is distressed, but she is not in pain. So, I think that's probably more about just being here and trying to articulate that'* (Denise, daughter, PC, 6 September 2015).

Denise described the world-of-being-in-aged-care as a complete contrast to Antonia's world before admission. The physical environment was *'so bland, clinical, and colourless, nothing like her own bright place'*. It seemed, however, that Antonia's lifeworld disparity, social isolation, and fear of death were highly distressing. She had had a *'life filled with colour, and I think that now being completely at the mercy of other people, and not be able to do anything, it's really frustrating and frightening'* and that *'she's gone from total independence ... to total dependence'* (Denise, daughter, PC, 6 September 2015).

The everyday world of Longleaf involved few social connections for Antonia, and her visitors were close family rather than friends. For Antonia, time with her family was *'heaven on earth. It's the only time I am not so lonely. I would die without them'* (Antonia, IC, 8 August 2015). However, for the majority of the day, Antonia sat alone in the dining room. As one staff member said, *'even for the residents with visitors, it's a long day when you are just sitting there'* (Meg, staff-RN, IC, 30 August 2015).



Figure 7.1 Dining room with separated residents.

Denise commented that Antonia was always positioned in the same location in the dining room and that she could not understand why residents were not placed together to aid social interaction. I asked staff about this, and it seemed based on unquestioned organisational routines rather than a deliberate agenda. *'Antonia has always been in that corner. I thought she must like it, so I don't ask her'* (Wayne, staff-CSE, IC, 12 September 2015). One staff member had a less favourable interpretation, *'they just keep people in the big living areas because it maximises supervision. Well, it just seems to be the place where people are dumped really, from the start to the end of the day'* (Donna, physiotherapist, PC, 24 July 2015).

Antonia wailed and cried out when anyone passed her chair, and whenever I spoke with her, she held my hand in a surprisingly vice-like grip and begged me not to leave. *'Please give me just a little more*



*of your time'. 'I need you, please stay' (Antonia, various impromptu conversations). It seemed that Antonia only felt at home when she felt connected to other people. My diary had many notes on Antonia's ill ease. 'Today Antonia told me that everybody working in the wing was "bad" and were out to get her saying "they all hate me, and I can't survive in here." The only time she was not anxious was when her family were present' (Journal, 9 January 2015).*

Antonia interpreted her separation to mean that staff deliberately kept her away from other residents. *'I want to help others. They are all lonely too, but the staff try to prevent us from being with other residents in case I talk too much, that's why they put me here' (Antonia, PC, 9 October 2015).* She described the staff as crooks and government spies but was worried, *'They don't want me to talk to other people, not ever' (Antonia, IC, 15 November 2015).* For the most part, she seemed to think hostile strangers surrounded her in the alien environment.

In light of the ethics approval condition to report suspected elder abuse, it is important to note that I did not observe any mistreatment and Antonia's daughter did not have any concerns about her mother's stories. Instead, I interpreted the conversations as symbolic of Antonia's fearfulness and sense of disconnection in a foreign environment.

Another of Antonia's fears was her belief that the staff were preventing her from seeing her family. *'I need someone to love me. We all need someone to love and take care of us. Can you tell the family quietly that I am here? They put me in a different room every week so that my family couldn't find me' (Antonia, IC, 15 November 2015).*

*'Mum is obsessed with good and evil', which Denise interprets to mean that 'I think she is worried about where she might end up. I think she is frightened of death' (Denise, daughter, IC, 6 September 2015).* Antonia spent her days in the dining room watching other people and related that she was aware that the composition of people frequently changed. It was relatively common for residents to be transferred to the hospital or moved to their room when unwell, but Antonia appeared to have filtered such changes as a *'disappearance'* due to *'something bad by the government [staff]'*. It seemed at times, a metaphorical turn of phrase representing her understanding of other residents' deaths. Denise confirmed this understanding, *'I don't know. I think she's scared of death. She'll say, "Oh that one's gone, they killed him". She's watching people; it's all she has' (Denise, daughter, PC, 6 September 2015).* In any case, it could be perceived as an expression of Antonia's ill ease and potentially having some awareness of mortality in the world-of-being-in-aged-care.

Antonia also seemed aware of stigmatism despite her cognitive impairment. She related that *'I saw many people never have visitors and I used to cry for them. In Australia, they call us oldies. It's an insult even though I am as old as Medusa; it shows their lack of intelligence. People don't like oldies. That's why we are all in here' (Antonia, PC, 30 March 2015).* She alluded to the building design being influenced by similar negative perceptions. *'They don't like us oldies. The rooms are too small for my family when they visit. I would rather be inside, but my room isn't nice enough to make me come out here where they always watch us' (Antonia, PC, 30 March 2015).*

Antonia's health noticeably deteriorated throughout the study, and towards the end of my fieldwork, she slept for the majority of the day in the dining room. She fell asleep several times during the follow-up conversation and was less coherent than previously. She explained that *'I just sleep a lot. I get so lonely. I don't want to be a grumble bum, but I like to have people here when I am awake. I feel more alive. I don't have long, really. I am just waiting now. I won't be around much longer' (Antonia, follow-up conversation (FC), 30 March 2015).*

Antonia may have been speaking symbolically, but as this conversation took place towards the end of my immersion in the world-of-aged-care, I did not know how accurate her statement was. However, she was not the only resident who spoke of an awareness of their imminent death.

For residents such as Antonia, their experience of Longleaf was that of distress and angst. Her days were spent in a paradoxical space occupied by residents who were simultaneously living and dying; the boundaries between life and death rendered more uncertain by the unpredictable trajectory of dementia. Staff must continue to care for the living and the dying within one building, in the case of Longleaf, at times in the same space, the dining room. This led to challenging spatial and social consequences that may have exacerbated Antonia's experience of alienation.

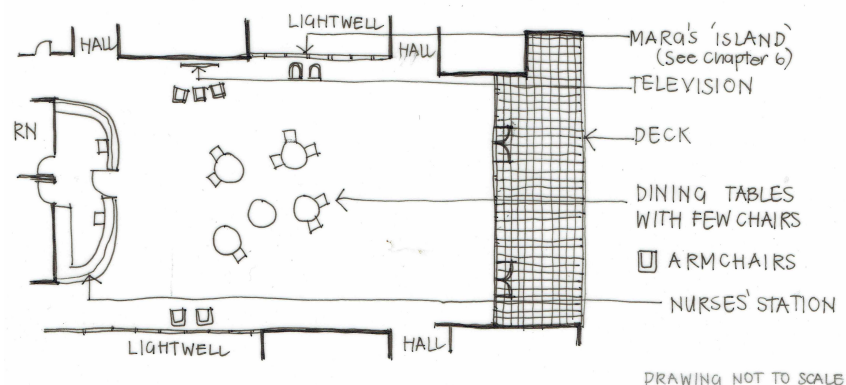


Figure 7.2 Dining Room furniture plan: showing the layout of residents in tub-chairs and furniture.

A staff member described the dining room where Antonia spent her days *'as feeling like a very big waiting room. People always seem to be just waiting.... it always feels like the start of the day. Except it doesn't start. People just wait'* (Donna, physiotherapist, PC, 24 June 2015). When I asked what they were waiting for, she replied quietly, *'they are just waiting to die'*. Her observation resonates with colloquial descriptions of aged care as 'God's waiting room' (O'Connor, M & Tan 2012; Parker, D 2011). For Antonia, her days were spent watching the other residents, and waiting for her family to visit so that *'the best part of my day'* would start, and perhaps as she alluded, waiting for death, *'it's better we don't talk about it, but I am just waiting now'* (Antonia, FC, 30 March 2016).

Several residents seemed to be *'waiting'* in the dining room. This was challenging for others in the dining room, as while some residents may be nearing death, for other residents, Longleaf is their home, and their families were continuing their daily or weekly routines and social visits.

The blurring of boundaries between life and death in aged care regularly produces organisational and care logistical problems (Worpole 2009). The building design of Longleaf did not always facilitate the privacy desirable in the final stages of life. I observed, at times, even those who were actively dying were brought out to the dining room for supervision while staff continued to care for the other residents. For Bob, a dying resident who was agitated and tried to remove his catheter and medication port, it was essential for his safety to be in the public space. This was not without conflict as other residents and family seemed to find the experience disconcerting.

Thus, not only was being-in-the-world-of-aged-care a paradoxical place but spaces within the wing, such as the dining room, were also strangely contradictory. The process of dying could be perceived as an in-between world, the person not fully engaged in living yet not dead either (Brown, M 2003), and the dining room itself was, therefore, a liminal space for those waiting to die. For Antonia, the dining room was a space of innumerable strangers in varying stages of moving towards the end of

their life. Dementia may have reduced her capacity for clear verbalisation and conscious recollection, but her lived experience of alienation and fear were articulated sufficiently clearly to convey her meaning.

Antonia's understanding that residents '*disappeared*' from the dining room was not unfounded. Bob was eventually moved to his room where he died the following day. Mary, as we shall see in her story below, was a conspicuous dining room resident but as her health declined, she spent more time increasingly in her room, eventually dying in the hospital.

Furthermore, Antonia demonstrated a profound awareness and was able to relate her understanding of her stigmatisation in contemporary western society succinctly. Although frequently assumed otherwise, it has been found that even those with late-stage dementia may still have the cognitive capacity to feel humiliated when they understand that they are treated as a lesser person (Sweeting H & Gilhooly 1997).

Antonia expressed a feeling that her age and frailty negatively affected others' perceptions and the way she felt she was treated. She described a sense of isolation from the world and her previous social connections. She also felt obstructed from forming meaningful relationships with others within Longleaf. It was a state of Being that hindered relief of emotional and spiritual suffering and experiences of feeling in place or '*at-home*' in the world-of-being-in-aged-care.

Antonia believed the chairs were arranged to keep residents from connecting. While it was unlikely that staff were deliberately '*keeping me away from the others*' as expressed by Antonia, the separation contributed to her sense of alienation and anxiety in the world-of-being-in-aged-care. For Antonia, Longleaf was experienced as an isolating separation from the outside world, within which she felt further isolation from others inside the RACF.

Unlike in the family home, the RACF accommodates numerous people who are dying, forty in the case of Longleaf. The dining room was experienced as a space that was disturbingly unlike Antonia's previous known world, a space with strangers with whom she was unable to connect and where the blurring of boundaries between the living and dying were incomprehensible to her and fear-evoking.

The experience of Longleaf for Antonia was dominated by anxiety except during family visits, which was similar for many residents, including Mary whose story follows.

## 7.2 Ageing-in-place and dying-in-place

### **Mel and Mary's Story: 'It wasn't meant to be like this'.**

Mary was 85 years old with a heart condition as well as dementia. She had a clever wit and well-developed sense of humour that remained evident despite a diagnosis of dementia and fluctuating cognitive capacity. She was, however, often anxious when her family were not present in the wing, exhibiting an odd sucking in of breath that her daughter said was a sign of distress. Mary actively avoided being alone, moving around the dining room attempting to strike up conversations with other residents and staff.

Mary had raised her five children as a single mother and now had several adult grandchildren living locally. Mary had visitors on most days who similar to Antonia's family were able to appropriate a space in the dining room where they often played cards together. '*Just as well mum had a big family, six kids. Now she is well looked after when she needs it most, not like some of the other poor buggers in here*' (Mel, daughter, IC, 29 July 2015).

Mary had been transferred directly from the hospital a few weeks after my fieldwork had commenced and while Mel compared Longleaf favourably to other RACFs she had inspected, she spoke of admission as challenging. *'It's all happened so quick. I didn't want to believe my mother would end up somewhere like this... but yeah...it's taken me some time, you know, to get used to it'* (Mel, daughter, PC, 28 August 2015).

Mary had been keen to participate and had provided consent to be involved in the study, but her health declined before our prompted conversation could take place. Her oldest daughter, Mel participated in a prompted conversation. Both Mary and Mel were involved in multiple impromptu conversations. Although all resident stories were to some extent their family member's story, Mary's story was told predominantly through Mel's voice because it was about dying in the world-of-being-in-aged-care and an experience of death that challenged Mel's ideals of a 'good death'.

Initially, Mary was relatively mobile, spending minimal time in her room beyond sleeping at night and the occasional nap. *'She would rather be out there in the noisy dining room. I don't know how much time she spends in her room, really. She only goes to sleep I think'* (Mel, daughter, PC, 28 August 2015). Thus, Mel had not personalised Mary's room but said *'The contract says we can't bang anything into the wall, but it doesn't really matter as mum only sleeps there'* (Mel, daughter, prompted conversation, 28 August 2015).

Similar to several residents' stories as told in Chapter 6, Longleaf was the place where Mary 'stayed' rather than resided more permanently. Mary did not understand that she was now in the world-of-aged-care and she seemed to have little if any, personal connection with her bedroom. *'Actually, just driving back here today, I said to her, "What do you want to call the place where you've been staying?" Because she has her home, where my brother still is with her dog... And she said, "Room 12, that's what's written here". 'So, she's not even saying 'my room' yet'? (Researcher). 'No, it's just room 12'* (Mel, daughter, PC, 28 August 2015).

Each time Mary returned from several relocations to the hospital, she spent more time sleeping and seemed noticeably frailer, and her communication and cognitive capacity diminished. *'She seems to be so much more confused since she came back this time. She can't even remember my name today'* (Mary's granddaughter, 4 October 2015).

*'Both Mary and her daughter Mel had been a lively presence in the dining room. Unlike most of the others in the dining room, they had both engaged with other residents and family. Their absence as Mary spent more time in her room changed the dynamic in the dining room, which felt noticeably quieter and more subdued'* (Journal, 15 October 2015).

Mary died in hospital in early November having spent four months in Longleaf. Unlike many of the other residents, Mary died with family members around her. Mel, however, was not able to be present as she was holidaying, and by the time she was able to return to Australia, *'she was gone already. I didn't make it. The staff said to go, to enjoy life.... I thought she would be OK'* (Mel, daughter, phone call, 20 November 2015).

As Mel visited daily, I had become quite friendly with her and felt comfortable about phoning to offer my condolences following her mother's death. Mel expressed appreciation for my call but was upset and crying. Her primary source of distress seemed that her mother had *'died in hospital. She was supposed to be in there [Longleaf], her home, not in a cold hospital'* and that Mel had been unable to be present, *'I wasn't there. The staff said she would be all right, but I couldn't get back. She died without me'*. Mel, it seemed accepted Longleaf as home even though her mother did not.

Mel and other families did not define how a good death could be experienced. They were, however, clear that dying in the hospital was not their ideal. *'It wasn't supposed to be like this. It's so bad, so bad, and I feel so sad and guilty and just so awful. It's all just so wrong'* (Mel, daughter, phone call, 20 November 2015).

As discussed in Chapter 2, families regularly do not understand dementia to be a terminal illness. The dying trajectory is uncertain and unique for each person. It was clear from my conversations with Mel and other family participants that there was very little understanding or acknowledgement of the relationship between dementia and dying. There seemed insufficient, if any, communication from staff to families about the prospect of death. Mel booked an overseas trip on the basis that *'they [staff] said mum would be fine'* (Mel, phone call, November 2015). Given the lack of conversations and the hidden nature of death within contemporary western society in general, families were at times, unprepared.

Similar to many Australians, Mel had assumed her mother would remain not only in Longleaf but also in the same room *'for the rest of her life, as this is her home now, even if she doesn't realise that'* (Mel, daughter, PC, 28 August 2015). The staff, however, related *'residents get taken to hospital to die all the time'* and implied that transfers were, at times, unnecessary.

Mary's multiple transfers due to pneumonia and eventual death in the hospital were not unusual, and several residents died in hospital during this study. While Mary reportedly did not die alone, her mother's death in the hospital rather than Longleaf and her absence coloured Mel's perception of her mother's death as sub-optimal.

### **7.3 The resident's room 'where everything happens' in their final days**

#### **Tom's Story: 'I am not going to be here much longer'.**

Tom was 87 and had been a Bedroom Resident for almost two years. Prior to entering Longleaf, Tom had lived in an independent living unit in The Village with his wife, Bernie. He had fallen and broken his pelvis, and as his wife was no longer able to care for him, he transferred from the hospital into Longleaf. Thus, Tom was unable to walk or stand. He was bed-ridden and had not left his room since his admission.

He frequently reminisced about his exciting past as a master mariner, doing war service on a merchant ship in the China Seas and living in Fiji. Tom *'loved a chat'* (Anna, CSE), but other than Bernie, few people found time to sit with him, and he did not know any of the other residents.

He was gentle, softly spoken, and charming, and our many conversations were enjoyable. The prompted conversation with Tom was one of the shortest of all, lasting just under 20 minutes although no less profound or rich than more extended conversations. In that short time, Tom conveyed distress about not *'being in the same building as my wife'*, considerable insight about his lived experiences of confinement to his room and his pending mortality.

Tom's room was not personalised for his needs; instead, the emphasis seemed to have been more about providing for Bernie's comfort. The room had partially been recreated as a living room including a recliner chair and knee rug for Bernie. There were a few groceries such as sauces, salt, pepper and sugar, cutlery and china cups and a knitting bag with a project *'to give me something to do while I sit here'* (Bernie, wife, IC, 28 October 2015). *'This is where everything happens now, and we spend so much time here, it had to be comfortable, especially for me. We brought in my chair. We spend a lot of time here, but it's all in Tom's room'* (Bernie, wife, IC, 15 November 2015).

Customising rooms was potentially beneficial not only for residents but also for families to *'feel welcome'* in Longleaf. Tom confirmed that while *'I don't really utilise the room, it could be better for my wife'* (Tom, IC, 5 December 2015).

The room design was not ideal for their shared use and, as we saw in Chapter 5, the focus of the design brief was to meet residents' basic needs and facilitate staff care tasks. The limited room size meant that Bernie had to leave the room whenever Tom was being assisted to use the bathroom, as there was insufficient space for her to remain while the lifters were in use.

Tom's primary concern throughout our conversations was his separation from his *'beloved wife'*. *'She's my everything'*. The most challenging aspect for Tom of being-in-the-world-of-aged-care was being separated from Bernie. *'The buildings are not right if we can't live together. We have been married over 40 years, and now I have a room here, and my wife lives in our house in The Village just because I can't walk. I don't really understand it'* (Tom, IC, 5 October 2015). At other times, he lamented that *'being with your beloved, surely it's not too much to ask'*.

A significant benefit of co-location of RACFs within The Village was the convenience for a spouse to visit. Bernie spent several hours on most days with Tom. *'He's not a good conversationalist these days, but he likes having me there'* (Bernie, wife, IC, 28 October 2015). *'He says to the nurses when they ask him "how is the pain"? "Oh, it's not here when my wife is here". So, I try and be here as much as I can. He would have me there all the time if he could'*.

Bernie tried to help Tom feel at home in Longleaf by bringing projects from home, and food to share, including a Sunday roast, so that *'he feels a little bit like being at home'*. When asked how a care facility should feel, Bernie said *'I think it should make people feel at home, pleasant to go to, you know. We can be here for hours'* (Bernie, wife, PC, 2 December 2015).

Bernie seemed to be trying to create some sense of normalcy within the world of being-in-aged-care. For many people, Sunday roast is considered symbolic of family togetherness and an important everyday ritual. Maintaining previous daily activities seemed to bring comfort to both herself and Tom.

Despite, or perhaps because of his diminished cognitive capacity, Tom continued to offer a cup of tea to anyone who visited his room. *'What he says sometimes when I arrive is "Oh, sit down and have a rest". He used to say that at home'* (Bernie, wife, PC, 2 December 2015). It seemed irrelevant that he was unable to make tea; it was the process of offering that appeared to provide some small comfort and remained as a remnant of his previous life.

Tom's physical and social world had been reduced to one room, and he often expressed feeling lonely. Tom's experience of Longleaf was similar to several other residents. He related that *'the best part of the day'* was when his spouse was present, but the remainder of his day spent mostly alone and asleep especially during his final weeks.

*'I am sitting between the bed and the window with Tom as he sleeps which he seems to be doing for most of the day now. It appears to me that his breathing has become less laboured. I can hear the bustle of daily life taking place in Longleaf, but in Tom's room, there is a sense of peace. Tom had told me recently that "he wasn't going to be around much longer". I can't tell for sure if my presence brings him some ease, relieving his sense of isolation he had spoken of previously, but it doesn't seem to be bothering Tom. I am certain, however, that it brings me some comfort that Tom is not alone'* (Journal, 18 December 2015).

Similar to other family members, Bernie explained that she and their children had not referred to Tom's admission as permanent and felt that he did not recognise that he was not returning to their home. *'He didn't realise that, um.....we just told him he was in there on respite and we've never said he's not coming home. But he seems to have ...he doesn't quite understand that he's here forever. Just last week he said, "It won't be long now". But strangely enough, he doesn't question being in here, you know'* (Bernie, wife, PC, 2 December 2015).

Bernie interpreted Tom to be saying that he would be returning to the unit to live. However, Tom conveyed a different understanding to me, that while he missed his home, he would not be returning. *'Home is about having things the way you like it and keeping it nice. Not like here. But I am not going to be around much longer, so it doesn't matter anymore'* (Tom, PC, 5 December 2015).

Tom demonstrated profound insight about his imminent death. *'One day I'll just lie in this bed and go. Well, I can't do much. I can't walk'* (Tom, PC, 5 December 2015). He spoke of having enjoyed his life, and touchingly, his concern for Bernie's welfare remained at the forefront. *'We have had a good life, and it might be easier on Bernie'*. In a conversation the following week he spoke of their life together and seemed quite at peace that Bernie would be well provided for, *'Her house is I think, very nice for her and soon she can enjoy life again. I won't be going back or leaving here'* (Tom, IC, 12 December 2015).

Tom did not leave Longleaf. Tom died in early January, less than four weeks after our prompted conversation, and before a follow-up conversation. When I returned from the Christmas break, I found his room occupied by a new resident.

While I was not present in the wing at the time of Tom's death, it was apparent that his family had been. Although Tom's family had understood that he would not be returning to the unit following admission, they had not perceived Longleaf as the place he would die and seemed unprepared for his death. The care manager related, *'The sons created a fiasco. Not many people think of end-stage dementia as being end-stage, and perhaps there isn't much in the environment that suggests otherwise'*, although she did not explain how the design elements of the RACF could help people to understand that Longleaf was a place where people died. She added *'...well, if you think about it, the population that is alive now has not seen that much death. It's very rare, actually, for them to be faced with death until they come in here'* (Jill, Care Manager, PC, 17 July 2015).

Jill had mentioned several times that *'Aged care is the new hospice'* and that she was disappointed in the Longleaf design model, which she thought out-dated. While she did not elaborate on how or if the environment should be designed to help so that Longleaf was understood a place of death, she felt that *'a welcoming place for the family, especially at the end'* was essential.

As Bernie lived in The Village, Tom's children had a place to stay on site when they visited. She related that they usually came for a few days or a week at a time, *'which was simply lovely'*. Presumably, the family were able to stay reasonably close by Tom during his last days. For most families, however, despite theoretical support for having family present when a resident was close to death, there was almost nowhere to stay within Longleaf or the Village. *'Well we do have a little unit, one unit for the whole village down Woop Woop where they can stay, but it would be nice if they could stay in the rooms, especially when they are leaving'* (Anne, staff-CSE, PC, 3 July 2015).

Alternatively, the staff said, *'we sometimes bring a tub chair so the family can sleep the night if they want'* (Warren, staff-CSE, PC, 24 July 2015). The rooms, however, were of a size to accommodate only one tub chair or armchair. In any case, I did not observe family stay overnight or for more than a few hours in the ten months of the study duration.

While the benefits of personalising resident bedrooms were discussed in Chapter 6, Tom's story demonstrates the potential value for families in being assisted to *'feel welcome'* and for the private bedroom to be reconceptualised to accommodate family needs. This was significant for bedridden residents, especially during the last days of life when some families wish to keep vigil. In a personal account of her mother's death, a researcher and interior designer described how decorating the room to be more functional and *'provide delight for mother and me'* was an *'act of love'* allowing her to *'do something for her mother's appreciation but also her own personal comfort'* (Tofle 2009; 2012, p. 168).

As residents' health deteriorates, their physical world became increasingly smaller. Lawton, M. P. (1977) refers to an environmental trajectory of 'environmental press' that parallels physical and cognitive decline. As dementia progresses and as death comes closer, the resident's world shrinks from the community to home, from home to institution, from institution to single room, and usually to bed. For some residents such as Tom, several steps may be omitted. His world was reduced immediately from community to bed, where he spent his last days, highlighting the importance of the design of bedrooms.

It is reasonable to assume there exists an underlying understanding and associated ill ease when spending considerable time in an enclosed world where death is common but not openly acknowledged. *'There are so many deaths here. Everyone must know. We try, but we can't really hide it'* (Jack, staff-CSE, PC, 25 July 2015). Accommodating the dying was, however, not explicit in the architectural drawings for Longleaf and, as discussed in Chapter 2, issues about death and grieving are generally avoided in RACF settings, as had been the case in Tom's story.

#### 7.4 Dementia, death and dying; designing for the unspoken

##### Richard's Story: 'Gone palliative'.

Richard was previously a school principal, described by the staff as educated and cultured. Anne told me that he was a kindly man, popular with the staff and that he had spent the whole of his 15-month stay in his bedroom. Initially, this was by choice as he did not want *'to mix with the others who he seems to think he was different from'* (Anne, staff-CSE, IC, 30 June 2015), and later due to poor health. His only visitors were his son and daughter-in-law, but I did not observe anyone visiting Richard during my fieldwork.

Richard's interests had been football, cricket, swimming, rugby, and reading. Our impromptu conversations were usually about literature. He was keen to be involved in this study, but his health deteriorated rapidly. He had *'gone palliative'* and died within a few weeks of fieldwork commencement.

*My early understanding of 'gone palliative' was based on the literature and conversations with various staff who had spoken of personalised Advanced Care Plans<sup>9</sup> including music preferences and aromatherapy. Several RNs spoke of theoretical support for 'softening things' and 'making the room more calming and personal', but I did not observe any environmental interventions. I do not know what I expected, except that the experience would somehow 'be more' than it was. The only indication that something was different on the day of his death was that Richard's door was only ajar when residents usually have open doors, and the curtains were drawn. When I arrived at*

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<sup>9</sup> Advanced Care Plans describe how a person wishes to be cared for when they are dying or receiving palliative care (Australian Institute of Health and Welfare 2014). Access to Advanced Care Plans was only available to the RNs and not included in my Ethics Approval.



*Longleaf today there was no mention of Richard's status, no changes to the normal daily routine and none of Richard's family were present. I asked about Richard when I noticed his room was darkened and was told he had 'gone palliative'. I asked the RN what 'gone palliative' means and she answered, 'it means that morphine has been commenced' (Jackie, deputy DON, 15 August 2015).*

*'Richard lies alone in his room, and he is sleeping on his back with his mouth open. I don't see staff or family sitting with him, and he lies under the glare of the downlight strangely positioned directly above his head. His bedroom door is always wide open, and I am struck by the indignity of dying so publicly, yet if the door had been shut, Richard would be even more isolated. I am sad that a man with a seemingly rich life is reduced to a condensed one page 'Life Story' and a lonely dying process in an isolated yet paradoxically public space' (Journal, 10 August 2015).*

While the staff theoretically supported person-centred-care and the notion of a 'good death' where people do not die alone, translation into practice was limited. Several of the staff spoke of how residents were well supported by the company of families or staff while they died. Others gave contradictory accounts that suggest, for the most part, residents died alone. *'So very, very lonely. They are by themselves in their room. No one is coming. So sad, so sad. We check but we come back, and we just find them. They died with nobody. Very hard for me, so sad'* (Connie, staff-CSE, 10 July 2015).

Richard was one of the residents who died alone. I had been present in Longleaf from 3 pm until 7 pm on Friday and did not see anybody enter Richard's room. *'By the time I arrived at 11 am on Saturday, Richard's body had been removed. Although his father had only died sometime Friday night, his son had been asked to remove his father's personal belongings. It was clear that he was shaken but borrowed a trolley and wheeled his father's belongings out through the dining room. Richard had more personal furniture and paintings than most residents significantly, and thus the indignity of wheeling the belongings of his very recently dead father happened three times. This was the last sign or mention of Richard. I wonder if death is so commonplace in aged care, that today is little different from any other day for the staff. I speculate at this stage about the potential impact on the family and residents of being faced so directly with death. What meaning do they make of half-shut doors, followed by closed doors with a "Do Not Disturb" sign used only when someone had died, and their body not yet removed, but nobody speaks about the death or the person who has died'* (Journal, 30 August 2015).

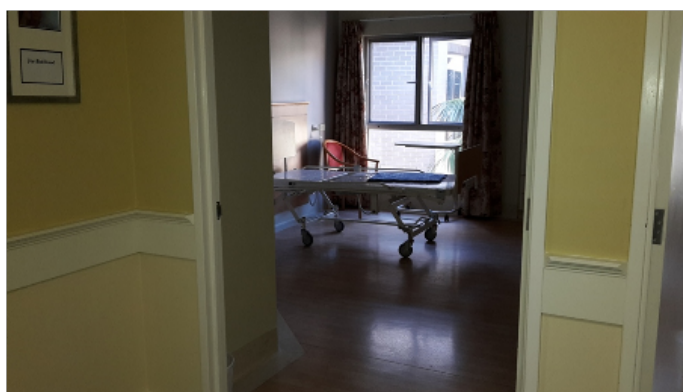


Figure 7.3 Left photograph- 'Do not disturb' sign hung on the door following the death of a resident until their body had been removed. Right photograph- Bed from the hallway: the door was opened.

I observed that usually, a room had a new occupant within 24 hours of the death of the previous resident, sometimes less. Some scholars imply criticism suggesting the RACF has become profit-driven, and commercial viability is dependent on rooms being maximally occupied at the cost of sensitivity (Komaromy 2000). However, there was a long waiting list for admission to Longleaf, and the balance between the needs of those grieving and those experiencing stress waiting for a place in Longleaf was challenging.

While I was not present when Richard's body was removed from Longleaf, I had analysed the architectural drawings and noted that there appeared to be no provision for discrete removal. Several staff discussed the issue of the removal of bodies. *'And the most important thing that we should not miss out is the dead body. When it goes, it goes through the main dining room. Those who have good cognition and maybe even the others, they see, and they know. The dead body goes right in front of the eyes and even those people with dementia; they know what this is about'*. He acknowledges the reality of life in the RACF. *'So many people die here, sometimes it can be one or more a week. Why didn't they think about that'* (Ben, staff-CSE, 26 June 2015)?

Several staff gave accounts of bodies removed through the dining room, but meaning-making by residents, family, and staff of the experiences was variable. Some were horrified and aghast at the lack of consideration in the design by architects and managers and the indignity and inappropriateness for the person and family. Others spoke conspiratorially as if transfers through the public space were not known but incongruous, nonetheless. Some staff were somewhat accepting that *'Yep, it's the only way out'* (Meg, staff-RN, IC, 15 September 2015).

Some weeks after Richard's death, I was in Longleaf when another resident died. *'A resident died at 10.30 am today. It was so low key that I had no idea of what was occurring. According to the RN, he had only 'gone palliative' last night and commenced on morphine'* (Journal, 18 September 2015).

Not long after the RN told me that the resident had died, his bedroom door was shut and a *'Do not disturb'* sign hung on the door. *'After spending some time in the world-of-being-in-aged-care, I speculate that some residents and family must come to learn what the 'sign' represents, even if nobody is talking about it'* (Journal, 18 September 2015).

One staff member suggested that it could inform my study to observe the removal of the resident's body. *'It will be interesting for you to watch what happens over the next few hours. You know there is only one way to get the body out, but that won't be until after the doctor comes to certify'* (Donna, physiotherapist, IC, Friday, 18 September 2015).

Donna said *'Working in this area [aged care] desensitises people and that is a necessary survival mechanism. But we do forget what it might be like for other people such as families'* (Donna, physiotherapist, IC, 18 September 2015).

The day continued in Longleaf as usual. Staff continued caring and went home at the end of their shift and the families that usually visited came and went from Longleaf, back to the outside world. It would seem to be just another day in the world-of-being-in-aged-care, except that for some people their world has just changed, and their spouse, parent or friend had just died.

I stayed in the wing to observe as Donna had suggested. *'The resident had died at 10.30 am. His daughter arrived in Longleaf about noon, spoke briefly with the RN in her office, and went to her father's room. She left the wing a few minutes later carrying a large framed family photograph'* (Journal, 18 September 2015).

By 2.30 pm, one of the regular GPs had certified the death, and the funeral directors called by the RN, 'You can come anytime' (Meg, staff-RN, phone, 18 September 2015).

*'At 3.30, the funeral directors arrived. I find myself simultaneously strangely amused and disconcerted when I saw them. They were a cliché of what I might have imagined funeral directors to be: both tall, thin, pale and pasty, with slightly greasy hair, wearing a white dress shirt with black pants. Their appearance and demeanour left little doubt as to who they were and why they were in Longleaf.'*

*'They were familiar with Longleaf, the layout of the wing and with the RN. They cheerfully said 'G'day' to the RN but didn't even glance at the other residents and family sitting in the dining room. For them, it is just another day at work'* (Journal, 18 September 2015).

The body was draped in red velvet and wheeled on a trolley from Room 26 along the hall past 24 residents' rooms, and out of Longleaf through the corner of the dining room. There were 11 residents and two wives of residents in the dining room at the time.

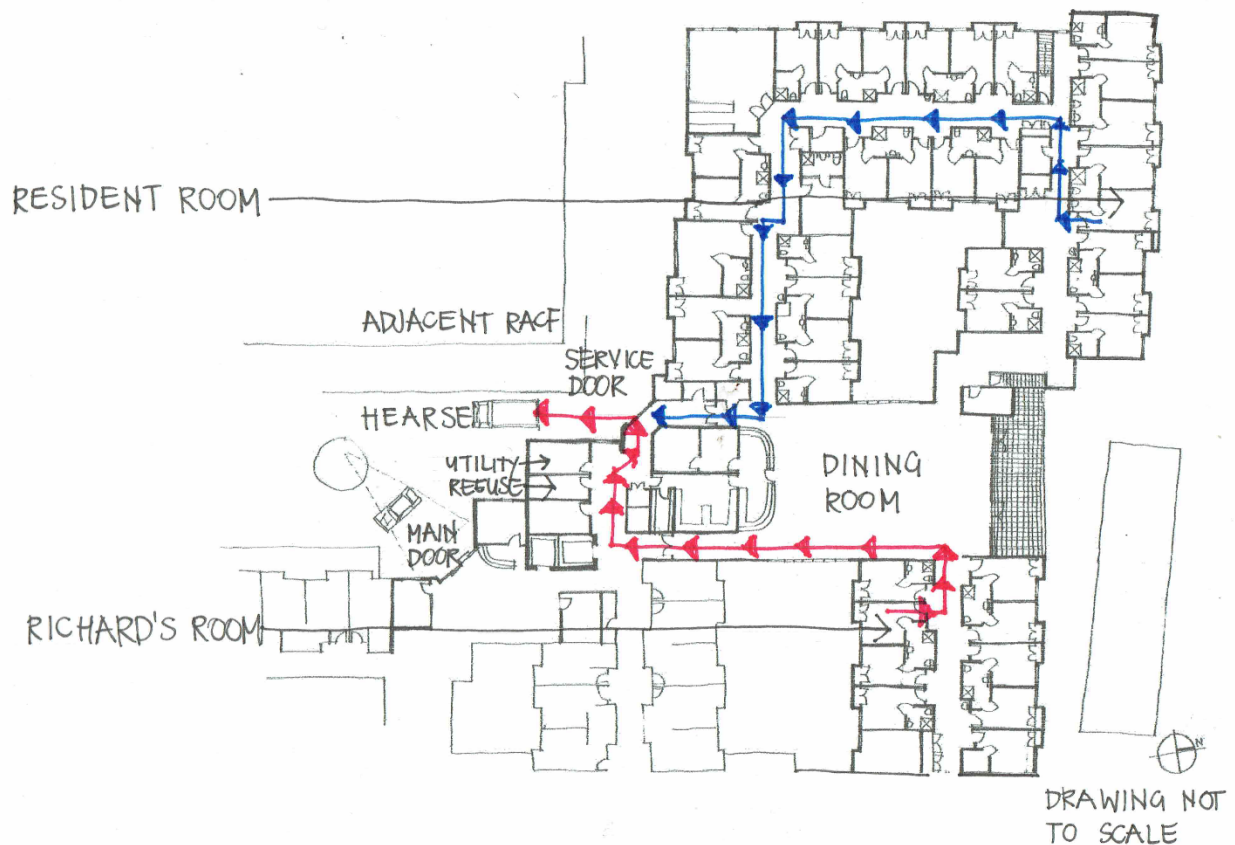


Figure 7.4 Floor plan showing the pathway of the removal of Richard's body and belongings (red). The path of the other body removal that I observed is shown in blue.

In my journal, I noted that removing the body was completed as efficiently as any other daily task. *'I don't quite know what I expected, but I did expect something to be different from the everyday routine, some allowances made that a person who lived in Longleaf had died and now their body is to be removed. There were, however, no adjustments made to the daily routine or the physical environment. Doors were not closed, nor residents moved out of the dining room or distracted. I am slightly taken aback that it is somehow too casual. I am undecided at this point about whether making so little fuss draws less attention, and that is helpful or whether some kind of clear but sensitive response that*

*honours the death of a fellow resident is more appropriate. I found the experience too bald, too blunted'.*

*'Some family and residents appear not to notice, but I couldn't be sure. Another resident's daughter came through the entry door just as the body is going out and asked, 'Who just passed away?' I observed the residents in the dining room. A woman resident noticed and looked visibly upset. One resident saw and immediately went to his room. I could only assume that the experience was distressing and perhaps a reminder of their own pending mortality' (Journal, 18 September 2015).*

Staff confirmed my understanding that residents had an awareness of others' deaths. *'I have seen a lot of death in my four years here. The other residents must feel that. Even if they can't speak, they get a sense of death, of what is happening and the feel of the place changes for a few days. They see all the bodies. They get agitated. Everybody knows' (Ben, staff-CSE, PC, 26 June 2015).*

Death and removal of bodies, however, is difficult to disguise in the world-of-being-in-aged-care, and in this study appeared to affect not only the residents and families of Longleaf but also adjacent RACFs on-site. *'The hearse was parked in the main entrance courtyard which was readily seen from the bedroom windows of three other wings. Residents sitting outside the exit door watched the trolley pass right by them and loaded into the vehicle' (Journal, 18 September 2015).* The same door is used for goods deliveries, dirty laundry and rubbish collection, and ambulance transfers. On the floor plan, the entry is labelled *'service entry'*. It may not have been intended as the door for body removal, but the only other door was the *'main entry'*.



Figure 7.5 Entrance: showing the main and service doors. The service door was used by families to access Longleaf, as it was the closest door. The same door was also used for deliveries, rubbish and dirty linen removal, as well as body removal.

## 7.5 Discussion

Staff working in RACFs have an undeniably tricky role looking after residents who are living and dying alongside each other. Scholars have described the process of dying as a liminal experience where the boundaries between life and death are blurred (Froggatt 2001; Komaromy 2000; Worpole 2009). Compounding this uncertainty is that the dying process for people with dementia often takes place in the RACF, a liminal space. The RACF is a place that is neither in nor out of the world, similar to the hospice experience described by Lawton, J (1998) and where those within may live with declining health, hovering between life and death for some time.

It seemed not until the last few days of life that the boundary between the living and dying became clearer. For the most part, this distinction was clinical and linguistic, rather than experiential, employing euphemisms seemingly to protect the living. Where the dying were labelled *'feeling poorly'* in Froggatt's (2001) study, in Longleaf, those close to death were spoken of by staff as having *'gone palliative,'* a biomedical rather than existential understanding of dying.

A spatial consequence of staff categorising residents who had '*gone palliative*' was that those close to death were mostly confined to their bedrooms. Notably, a few residents in Longleaf chose to be bedroom residents, but staff chose on behalf of the majority of bedroom residents based on whether they were considered '*gone palliative*' or '*more confused today*'. Similar to findings by Froggatt (2001) it was apparent that the dying in Longleaf were separated from the living. Unlike other studies, the bedroom doors remained open to the public corridors, and thus, the separation was somewhat incomplete and privacy lacking.

Parker (2011) found evidence that within institutions, dying patients are sequestered, and care is less than optimal. In many cases, the effort to screen off the dying further marginalised the most vulnerable within the institution. While there was a consensus among Longleaf staff that residents should not die alone, the majority including Richard and Tom were observed to spend many hours alone except for brief checks and care tasks by staff and occasional family visits. Most died alone as Connie and Molly, two CSEs related or were transferred to hospital.

Undoubtedly, there were occasions when transfers to the hospital were essential for medical conditions that could not be managed in the Longleaf. Frequent hospitalisation such as in Mary's story, however, for treatable conditions such as pneumonia has been criticised by several authors as potentially damaging (Ryan et al. 2009; Van der Steen 2010), as well as some of the staff in Longleaf. Unnecessary transfers are known to limit continuity of care, often leading to increased distress and confusion in the unfamiliar environment and some cases, contributing to further permanent cognitive decline and reduced well-being (Gjerberg et al. 2011; Van der Steen 2010).

The importance of family connection for resident well-being and the lack of consideration of family needs in the building design was made apparent in each of the four stories in this chapter. Family visits were '*heaven on earth*' for Antonia, and Tom counted the minutes each morning until his '*beloved Bernie*' arrived. Tom's family had made his room comfortable for Bernie, and both Antonia and Mary had a large and devoted family who visited regularly, were able to appropriate a space within the RACF, and had a considerable positive influence on the well-being of their relative.

Most Longleaf residents, however, had few visitors and experiences, not unlike those reported by other researchers where families visited less frequently over time, more especially as the toll of dementia appeared to reduce residents' ability for connection (Sandberg et al. 2002). Staff frequently spoke about friends and family becoming uncomfortable and actively if not consciously withdrawing from the resident as they became less able to communicate and drew closer to death.

Staff related that this was a common occurrence, as some believed that the person with dementia was not aware whether they visited or not because conversation and connection often became limited. They perceived the visits to be poor quality and of minimal value and started to distance themselves from relationships, behaving as if the person was already gone. Several family members, in previous chapters, however, spoke of wanting to spend time with their relative but felt uncomfortable in the Longleaf dining room surrounded by other visibly frail and declining residents.

Residents in several stories also expressed feeling discomfort about seeing other unwell residents. Further, Marg was visibly distressed when she saw Richard's body removed and Antonia was fearful and believed that the '*government*' was removing people demonstrating an awareness about the loss of other residents, death and dying in the space where they spent the day especially those who were immobile.

While the majority of residents in Longleaf were immobile, there was some that had relatively higher levels of mobility and independence. A pattern emerged where the more independent residents

tended to be present in the dining room only at mealtimes, while the less mobile spent the whole day there. A further distinction noted was that residents in standard wheelchairs were positioned at the dining tables while the frailer residents in tub-chairs were placed around the perimeter of the room, separate from others.

Residents with better communication were able to convey their social and spatial preferences, but those with cognitive impairment were less able to do so. The spatial arrangement seemed more about the tub-chairs as furniture than about the residents, *'The chairs are just plonked for the whole day so the staff can see. It's not about what the residents want'* (Donna, staff-physiotherapist, PC, 24 June 2015). This arrangement may have improved supervision by staff, but families and residents interpreted the situation differently. One family member conveyed that *'staff think I am a cranky woman because I keep insisting mum is not put in that far corner where she is ignored and forgotten'*.

It seemed that the design of the environment had not been considered to support staff to care for the most infirm and dying residents in either the dining room or their bedrooms, despite their predictably high-care needs. Neither space was ideal, but bedrooms offered more privacy for the dying rather than the shared spaces.

The question of shared or single rooms while people are dying in RACFs was not definitively answered. On the one hand, three staff who had worked in the previous nursing home replaced by Longleaf suggested that the sense of isolation had been exacerbated by the predominance of single bedrooms in contemporary RACFs. *'Residents without families still had other families around them and had the other residents too in the old home'* (Jan, staff-RN, PC, 28 August 2015).

While I deemed it inappropriate to discuss end-of-life issues directly with residents or family, staff were more accustomed to seeing death and dying and therefore more comfortable with specific questions about the building design to support the dying process. *'The fact that everyone's got a single room, I find that that is supporting because you've got your own space. Are they big enough? No. I mean, in palliative care, what I would like to see is that you have some special suites with a lounge room, tea and coffee, microwave, and space for the family to bunk down if they want to stay and just having their own space'* (Meg, staff-RN, PC, 3 September 2015).

Staff consensus was that the wing had not been designed to accommodate the needs of the dying and their families, *'Well, they [architects and CEO] probably didn't think about it at the time. If they did, I don't think that they gave much thought into the fact that they, the residents would have family around them'* (Anne, staff-CSE, PC, 3 July 2015).

The majority of family and staff in Longleaf, however, assumed single rooms to be the better option, *'Definitely their own rooms. In some other facilities, there are four beds in a room, and this makes it difficult for families. They need to say private things to their relative when they are dying but feel shy when other people are there'* (Connie, staff-CSE, PC, 10 July 2015).

Several residents spoke of potential companionship, including Maree in Chapter 5 who related that she would like to share a room *'with the right person'* to alleviate her loneliness. Anderson (2013) found that some people may be disturbed by the groaning of the dying and perceive them to be suffering or become distressed by others' mortality serving to remind them of their pending death. Some people in a palliative care unit study were comforted and benefited from an acceptance of death shared by their room companion (Anderson 2013).

One staff member suggested that a choice of room types might be beneficial, that two beds offer the *'best of both worlds'* and several staff proposed a *'dying suite that includes family accommodation'* as

possible solutions. Nonetheless, to consider possible options, an open acknowledgement of the role of the RACF to support the dying would be required and buildings designed accordingly. The lack of conceptualisation of RACFs as places of death by families as well as architects and organisational managers has several negative implications, which are discussed further in the following chapter.

Critical issues in the design of the Longleaf as a place to die evidenced in the stories is the lack of privacy strangely juxtaposed with challenges caring and watching dying residents. It was also apparent that the need to remove bodies and the entrance design had been poorly considered. The design focus on providing clinical care for residents seems likely to have led to the lack of planning for the high mortality rates, the social needs of the dying, or the need for facilities to support families to '*feel welcome*' and have their needs accommodated especially in the final, intense days of their relatives' lives.

Many families remained engaged, but this is not without issues, especially in their relative's final days. Mel was considerably distressed by Mary's transfer and death in hospital. Although Mel's preference was for her mother to die in the family home, Longleaf was considered her proxy home, although not by Mary, upon admission. Her unmet expectation that Mary would die-in-place within Longleaf seemed mostly because the RACF had not been conceptualised or designed as a place of death.

Instead, aligned with O'Connor and Pearson's (2004) discourse analysis of Australian care organisation mission statements, the 'Values and Vision' Statement and marketing paraphernalia for Aged Care Inc. emphasised the dignity of the individual and fostering of independence. The organisation's webpage and brochures conceptualised aged care as '*retirement lifestyle*' with taglines such as '*adding life to years*' and included photographs of older couples walking on a beach or enjoying craft activities. The 'lifestyle' presented by the care organisation, at odds the dependence levels and relatively short trajectory to death of frail people with dementia, and the RACF lifeworld experiences related by the residents in this study.

Tom's death in Longleaf was no less upsetting for his sons than Mary's death in the hospital was for Mel. While Tom had seemed accepting of his pending death, his sons were not and were reported by the Care Manager as unprepared and distraught by their father's passing in the RACF. This may in part have been due to the lack of an explicit acknowledgement that admission to Longleaf was to a final place of residence and likely place of death.

Richard's story illustrated further the implications of the lack of practical consideration and design of Longleaf to accommodate the regular deaths of residents and the removal of their bodies. Corpses were wheeled out past multiple bedrooms and through the dining room where residents spent their day '*waiting to die*' and with little to do except watch others and try to make meaning of their lifeworld.

Together, the resident stories of lived experiences discussed in Chapter 7 demonstrate that the current design model and conceptualisation of typical RACFs, such as Longleaf, are less than ideal for living with dementia. I suggest that perhaps even more ill-conceived for death and dying primarily due to the paradoxically unspoken nature of death and dying during both the conceptualisation and production of RACF built spaces, and in the day to day experiences of being-in-the-world-of-aged-care. The overall sense is that lived experiences of people with late-stage dementia, their families, and the staff have not been clearly understood or considered with any depth by those involved in the production of RACFs, discussed further in the following chapter which draws together concepts presented in the previous chapters.



## CHAPTER 8: A CARE HOME SHOULD 'FEEL WELCOMING'

This study aims to explore the influence of the RACF built environment on the lived experiences of people living with late-stage dementia, together with those of family and staff to improve the conceptualisation of RACFs in Australia. Their experiences were presented as interpretive stories in the previous chapters as a way of engaging readers with this work and drawing them into the world of being-in-aged-care, deepening and adding to currently limited knowledge about the lifeworld of those with late-stage dementia. Woven throughout the stories were notions of participants' sense of disconnection from the self, place, others and the world, and the associated negative implications for their sense of wellbeing. Chapter 8 discusses my overall interpretations, and the meanings and issues related to the influence of RACF built environment on lived experiences, together with consideration of design implications and potential improvements.

Section 8.1 focusses on how participants try to make meaning of the RACF in relation to 'home' and experiences of '*at-homeness*'. Section 8.2 extends the notion of feeling '*at-home*' to the ability to form a place-attachment and sense of belonging within the environment. Section 8.3 outlines the qualities of the RACF revealed through the participants' stories for enhancing lived experiences of people with dementia in the final stages of life, their families, and staff. Section 8.4 reflects on the overarching concept of the need for the RACF to '*feel welcoming*'. Chapter 9 discusses the broader implications of the findings for architectural design practice and research.

### 8.1 '*RACF as home*': An unconvincing metaphor

The notions of '*home*' and '*homelike*' have underpinned the ideology adopted by aged care organisations, theorists, researchers, and to a lesser extent, architects with research about '*RACF as home*' dating almost thirty years. '*RACF as home*' is regularly perceived as the environmental equivalent of PCC, and the solution for the requirement for RACFs to be '*non-institutional*'. The literature review chapters, however, argued that there is little agreement on the definition of '*home*', and Fleming and Bennett (2009a) acknowledged that how to achieve a sense of '*home*' remains vague even in small facilities. There remains, however, broad consensus among scholars and aged care organisations that '*homelike*' RACF environments are a positive goal.

'Home' in Western culture generally, has powerful symbolic power, considered by most as a place of autonomy, privacy, and where we are in control and 'own' our space as highlighted in Chapter 3. Phenomenologists contend that people understand themselves and make meaning of place by contrasting their current situation with past experiences and places, usually the family home (Hellberg et al. 2011; Williams 2002). The current institutional context, however, was not only unfavourably compared with home, but none of the residents, except May, understood Longleaf, a typical RACF, as their '*home*' despite the ideals held by researchers, and the intentions of architects and care organisations. While several scholars debate the notion of '*RACF as home*' as discussed in Chapter 3, my research further evidences the questionable veracity of the metaphor, as understood through a hermeneutic phenomenological framework exploring lived experiences and differentiated from previous studies by the direct involvement of people with late stage dementia to provide an additional perspective.

It was clear that the family home and associated everyday activities had been the residents' key anchoring point, which they had relied upon to make meaning of their lives. As discussed in Chapter 3, while individuals hold various meanings for '*home*', it is generally considered the place of personal choice, control, and ownership, and centre of emotional and psychological security and stability. '*Home*' for many, is their '*sanctuary*' from the outside world, where they can let down their guard



and *'just be'*. Although RACFs provide a material shelter, Longleaf lacked the qualities of *'home'* that would support the residents' fundamental human need to *'dwell'* or *'be themselves'*. Threaded throughout the residents' stories are experiences of the loss of normalcy, previous routines, and practices of home closely associated with who they had perceived themselves to be.

Admission to the RACF was both a physical relocation and a symbolic separation from the residents' former lifeworld, family, and places that had supported their self-identity. The literal and metaphorical risk of being stripped of one's history and identity by the loss of personal belongings and home as described by Malpas (1999) is a common experience when residents move into an RACF.

Although feelings of *'at-homeness'* develop over time, residents experienced the move from the familiar home into the unfamiliar RACF as sudden and shocking at a time when their illness is advanced, and adaptability compromised. Not only is the residents' capacity to understand their place in the world damaged by the pathological symptoms of dementia, there are also few qualities within Longleaf to support their adaptation to an unfamiliar environment or the formation of place attachment or a sense of *'at-homeness'* described in the background chapters. The scale, aesthetics, social and lived experience of the bedrooms or the dining room bore little relationship to the family home that they seemed to remain attached to despite the passing of time. For the most part, the residents in this study did not appear to form a place attachment and were asking or striving in various ways to leave Longleaf.

Developing a sense of *'at-homeness'* through *'home-making'*, that is, decorating and making a space our own as a reflection of self-identity, was challenging in Longleaf. This customary expectation and assumed right within the family home were not supported by Aged Care Inc. Families in Longleaf perceived there to be limited capacity to tailor their relative's room due to both the design of the rooms and perceived institutional obstructions discussed further in Section 8.2.

While care organisations attempt to recreate the *'RACF as home'*, it is often limited to the insertion of domestic items into otherwise institutional rooms. While familiar objects are recommended by Chaudhury (2008) and Fleming et al. (2014), the *'homelike'* items in Longleaf were not integrated into relatable spaces and were poorly considered, inappropriately located, or seemingly token gestures. The objects were largely unnoticed and meaningless to the residents in Longleaf. Betty, for example, found the misplaced antique sewing machine *'disturbing'*. Rather than supporting her sense of *'at-homeness'*, the well-intended sewing machine added to her inability to place herself. Maree's constant *'begging to go home'* is a clear indication that she does not accept or recognise Longleaf as her place of residence. Neither Betty nor Maree knew where they were beyond *'not home'*.

While Betty and Maree were placeless, several residents believed that they were in the hospital but thought they were not sick, which added to their confusion and sense of displacement. They also expressed a feeling of powerlessness in a situation over which they felt they had little control. Joe was *'striving to rest to get well'* and thought he was being held against his wishes. May did not understand why she was in the hospital, *'I don't have anything wrong with me'* but felt she had no choice but to stay. Jean seemed one of the most displaced. In the morning when she awoke in what she understood as a hospital room, she despaired and cried out, *'what do I have to do? I feel so lost in here'*.

Similar experiences are likely in other typical RACFs with predominantly clinical environments creating a feeling of being *'out of place'* that is similar to the concept of feeling homeless discussed in Chapter 3. A critical issue identified is that while *'home'* seems to be interpreted by organisations, and at times staff, to mean a bounded space, for many residents, their call for *'home'* was

metaphorical. While Calkins (2009), and Schillmeier and Heinlein (2009) describe the longing or yearning to be for an emotionally significant place, rather than a bounded space, Betty and Joe, did directly compare Longleaf with the quality of their previous houses, reinforcing the complexity of the issues of the RACF positioned as 'home'.

Another essential process of home-making discussed in the background chapters is the significance of territoriality or adopting a space as one's own, assumed to be the residents' room. I found that even appropriating a small corner space or chair added to resident wellbeing. In Betty's story, the ability to arrange her belongings around her chair allowed her to have some sense of control and a personal territory distinct from the homogenised spaces of the remainder of the RACF. Marg had also been able to appropriate her '*own little isle*' on the edge on the dining room providing her with a sense of being anchored within the otherwise amorphous space. While both women only had a tenuous hold on the spaces, this suggests that territoriality and the sense of autonomy and agency it provides remains significant and desirable, although elusive for residents with late-stage dementia in RACFs.

For the most part, however, residents were unable to appropriate, or protect their territory even in what is ostensibly their 'own' bedroom. As Hauge and Heggen (2008) stated, ownership boundaries within the family home are clear and understood, and there is usually an expectation that spaces can be controlled including the power to invite or exclude others. In contrast, the delineation between the public and private spheres in Longleaf was confusing and indistinct especially in the context of the residents' bedrooms. The significance of doors for providing boundaries within the family home has been discussed previously, especially the notion of the front door sharply separating the home from the world outside. However, in Longleaf the door offered no such power or symbolic control mechanism. There was no door-snob, staff entered bedrooms without requesting permission, and there was an unspoken rule that doors were kept open except when a resident had died.

In general, defensible threshold spaces of the 'home' are often missing in RACFs and most notable is the lack of a nuancing between the private bedroom and public corridor. For Heidegger, some of the symbolic places within the home constitute places of intimate contact with others including the hearth, threshold spaces, and verandas (Heidegger & Hofstadter 1971). Van Steenwinkel et al. (2017) and Barnes (2006) also identified that it is through graduations, layers, and in-between spaces, where people can establish a sense of privacy and territory for the self, thus distinguishing between public and private spaces to alert others of ownership.

The lack of provision of such spaces, however, disallowed vital processes of meaning-making and developing a sense of '*at-homeness*' by the residents of Longleaf. In addition to providing an opportunity for personalisation, Barnes (2006) identified that the threshold serves as a reminder to staff that they are entering the resident's space. Fleming (2011) also suggests individualised doorways as an orienting device for people with mid-stage dementia. While less critical for wayfinding purposes for people with late-stage dementia due to frequent immobility, passing through a threshold space is often experienced as an embodied change of place. A tailored recessed doorway could serve to anchor the resident within their room and the RACF through the use of multiple meaningful cues such as colour, large portraits, name signage and other personal objects as they cross the threshold into their private room.



Figure 8.1 Identifiable Doors. Personalised doors and thresholds with multiple cues to support the residents to identify their bedrooms. Threshold space between the public corridor and private bedroom. (Image from <https://dementia.stir.ac.uk/design/virtual-environments/virtual-care-home>)

Recessed door niches may not always be viable due to budget or space limitations, especially when renovating existing RACFs. Doors could be individualised with colour and decorative design features including windows, knockers, panelling, and varying materials. Spatial graduation and territorial control could also be afforded through other devices such as a window in the door or wall adjacent to the corridor. A curtain or blind would afford an option for privacy or connection, providing residents such as Marg, with a sense of personal control during the concert.

Thus, while they were referred to as *'residents'*, there was little sense of resident control or ownership in Longleaf, or that it was designed with the residents' needs as primary. As discussed in Chapter 3, the RACF has different meanings and functions for different stakeholders creating conflicting and contradictory requirements within the one environment.

As reviewed in Chapter 5, the focus of the design briefing notes for Longleaf was staff task efficiency and the clinical and functional requirements of a perceived homogenous resident group and seemed to overlook residents' changing needs as they moved closer to death. The single living room and centralised nurses' station is a typical design response prioritising organisational and staff needs over others in the reciprocal care relationship, although research has found that this typology is often perceived as a barrier between staff and residents (Sixsmith et al. 2013). Further to Sixsmith's findings, in this instance, the nurses' station was somewhat erroneously designed to look like a hotel bar which added to residents' confused experience of the dining room.

The dining room was the space in Longleaf most frequently reported in negative terms by staff and family. While Marg described the dining room as *'nice'*, most participants described the room as *'too big'*, and *'too noisy'*, and that it was more like a *'hospital waiting room'* than a recognisable dining room.

The dining room was particularly challenging for the residents who were often placed for the whole day in the alienating space. This finding is especially significant for people with late-stage dementia accompanied by frequent immobility issues and inability to make independent choices about where they spend their days. Similar to many RACFs, the room was not merely a place for dining and sitting. It was a vast multi-purpose room argued by Zeisel (2013) to cause confusion and distress for people with dementia. Together the non-domestic activities, size, and fragmented aesthetics of the dining room presented challenges in interpretation for several residents including Jean who thought she was a non-member in *'the club'* and had to pay for her meal.

Without a range of spaces in the RACF, many non-domestic activities took place in the dining room. In Longleaf, physiotherapists exercised and rehabilitated residents in the dining room. At times, staff weighed residents and dispensed medications in the public space. The use of the space was clinical

and controlled by the staff, which together with the focus of design on bodily care flies in the face of PCC and valuing the whole person. This creates an environment where the workplace qualities outweighed the qualities of home, confusing residents and reinforcing both residents' and families' sense of the RACF as an institution controlled by staff.

While not discussed in previous research, I had regularly noted that while at times, there was a perception of activity in the dining room, it usually only involved a single resident receiving physiotherapy, and one resident being visited by grandchildren. Antonia felt deliberately '*kept away from the others and things that go on in here*'. Residents related feeling lonely although they were paradoxically surrounded by people. Often however, they were effectively excluded, and conveyed a sense of being an '*outsider*'.

Whereas most residents were uncomfortable in the single living room, Marg and Mary (before she became bed-ridden) chose to sit in the space as it offered the most, but rarely realised, potential for informal exchanges. Other residents, such as Greg and Joe did not want to mix and may prefer quieter spaces more closely aligned to normative experiences within the family home that support intimate conversations and options to dine with only a few other residents or their family.

There needs to be an assortment of private, semi-private, and public spaces, nooks, and niches adjacent to the central spaces where one can sit quietly to observe and choose whether to engage or not, rather than the '*all or nothing*' spaces typical of most RACFs. While a single living space potentially maximises supervision, participants, including staff, almost universally recommended a choice of smaller dining and living spaces implying that care provision was manageable.

Families and residents related feeling distressed by other unwell residents and distracted by noise in Longleaf, which made social interaction challenging. Providing a variety of spatial options would deliver a more nuanced solution likely to appeal to individual tastes, requirements, and changing cognitive capacities as well as offering experiences more similar to home.

A range of spaces would allow for various concurrent activities rather than single institutional events such as the concert described in Chapter 5 and activities that involve one or two residents while seemingly to exclude others in the same space. There are, however, several complex design challenges beyond only providing additional living rooms. Careful consideration of the quality and location of spaces to support residents' various needs is required. In addition to providing more imaginative spaces, small lounges and niches could include places with framed and ideally active<sup>10</sup> views, places to sit with music playing, postcards or picture books to look through, a fish tank or bird aviary, puzzles, or an indoor garden to encourage interaction and provide a range of sensory experiences.

Also missing were the opportunities for normal, every day activities. Both families and residents perceived there to be physical and regulatory obstacles to many of the usual practices of 'home' such as making a hot drink or a sandwich. While there was no resident or family kitchen within Longleaf, many participants interpreted the nurses' station as a barrier preventing entry and felt that entering the central kitchen was '*not allowed*'.

Phenomenologists contend that it is the repeated, normative practices of home carried out over many years that anchor us in time and place. The stories in this study illustrate the loss of continuity

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<sup>10</sup> Active views could include trees and gardens where birds visit, the change of season is recognisable as leaves and blossoms change, or where there are activities to view such as a children's playground or community walkway with people passing by.

and disconnection from residents' previous way of life and self-identity. While the literature usually discusses 'home' in general terms, specifically identified practices of home took on considerable significance and came to represent how the RACF is '*not home*'.

Previously centred within the family home, taken-for-granted daily routines and practices that afforded meaningfulness and structure to the residents' day were not provided for within the RACF. There was no garden for May to enjoy her '*morning coffee*', no wall mirror for Jean to coordinate her outfits, and no small lounge for Mary's family to do the '*crossword we have always done together*'.

Although aesthetics have a significant impact on the residents' ability to recognise the RACF as their place of residence, it was the lost practices of home and the need to feel '*at-home*' that were discovered to be more meaningful. The limited but growing research to date about the notion of '*at-homeness*' in RACFs focusses on people with mid-stage dementia, but these findings indicate a continuing awareness of these complex and essential concepts well into the disease progression.

For the majority of residents and family, it was apparent that '*normal life*' and the '*little things*', lost lifelong habits and normative practices of home, represented key aspects of their experience of feeling displaced and '*not-at-home*'. '*I miss tea that is hot and made from real leaves*' (Marg, resident, IC, 22 October 2015) and '*making myself a cuppa whenever "I" feel like it*' (Betty, resident, IC, 10 December 2015). For Joe, '*Sitting on the deck with my wife, sharing a pot of good coffee always used to make me feel better when I was low*'. The design of the built environment requires reconsideration to support practices of home, as they remain relevant even for those most cognitively impaired.

Despite widely accepted notions of PCC and '*RACF as home*' by academic circles and the aged care industry, the clinical model of care that Ortigara and McLean (2013) argues remains mostly in place also continues to result in a hospital-like RACF design typology. Casuarina House exemplifies this issue with overly large living spaces, central servicing and supervision, and impersonal, institutional aesthetics as described in Chapter 5.

In my view, the design typology has remained relatively unchanged since the first purpose-built RACFs in the 1980s described in Chapter 3, and the design process is similar to when I worked on RACFs architectural projects in the late 1990s. Without a new design framework, the current drivers of design, objective standards with little subjective guidance will continue to create hospital-like environments where residents and family rarely, if ever, feel '*at-home*'.

Supporting residents to feel '*at-home*', a notion closely related to the phenomenological notion of '*dwelling*', is a worthy aim as the RACF is where they will spend their final months and are likely to die. As discussed in Chapter 3, a fundamental characteristic of what it is to be human according to phenomenologists is to be always striving towards a place of '*dwelling*' where we feel '*at-home*' within ourselves, with others, and within the world. The idea that this can take place in a variety of settings suggests that a sense of '*dwelling*' is achievable within RACFs, but this study argues that physical '*homelike*' features are not the only means.

Further, there is an underlying assumption of a universal need for the RACF to be constructed as 'home'. Significantly, this study contradicts this commonly accepted notion. Several residents and family members were '*not ready*' or did not want to accept the '*RACF as home*'.

While Tom accepted that Longleaf was the place where he would die and that he was '*not going home*', it was vital for Greg to believe his stay was temporary and that the RACF was not his home. Greg's wife was not ready to accept the '*RACF as home*' as it was '*too final*'. While Mel considered

Longleaf as a proxy home, her mother did not recognise the '*RACF as home*'. Instead, it was a nameless place where she had a room.

Paradoxically, while the majority of residents did not understand or accept the RACF as 'home', most of the staff and some families referred to Longleaf as 'home', often while discussing the lack of qualities to enable a sense of '*at-homeness*'. Their interpretation seemed by virtue of the RACF being where the residents lived, an intellectual understanding of physical location rather than a felt or embodied experience of '*at-homeness*'.

For some families, accepting the RACF as 'home' suggested an undesirable finality or permanence. Simultaneously, they also recognised the need for their relative to feel a sense of belonging and '*at-homeness*'. With the loss of the family home, Longleaf became the pivotal place for connecting with their spouse or parent, and for social interactions.

This thesis demonstrates that the human need for personal choice, control, and autonomy, territoriality and ownership of space, and normal, everyday activities associated with feeling '*at-home*' remain significant for those with late-stage dementia, seemingly until they die.

Further, this study evidenced considerable variation of understandings of home among only 31 participants. The various participant interpretations of the RACF as '*home*' or '*not home*', suggests that not only are individual resident needs variable, family and staff needs may be different, even contradictory to those of residents. These variations further reinforce the complexity of an individual's needs and meaning-making of the RACF environment, which is overlooked when theorists, managers, and architects interpret the RACF as 'home' as a physical construct. The residents' and families overarching need regardless of what they interpreted the RACF to be was to feel '*at-home*' or '*welcome*', a notion closer to Heidegger's concept of '*dwelling*'.

These findings suggest that the concept of '*homelike*' limits the capacity to develop strategies that embrace the complexities of lived experiences, of feelings of being '*at-home*' and of human connection to the self, to others, and the world. In Longleaf, '*homelike*' was the apparent design response to the '*unbrief*' for the need for the RACF to be '*non-institutional*'. The literal application of limited decoration and domestic items had not provided the residents or family with a sense of the '*RACF as home*' and overlooks the complexity and changing nature of understandings of home.

'*RACF as home*' becomes an unconvincing metaphor, perhaps not a realistically achievable aspiration or ideal. I am not suggesting that the RACF should not be considered as the resident's home or place of residence. Rather, this study further demonstrates that the current construct of '*RACF as home*' and how our understandings of '*homelike*' are currently applied in the design and provision of RACFs is not supporting residents, families, and staff sense of wellbeing and feelings of being '*at-home*', or the way they make meaning of the environment.

Notions of '*RACF as home*', especially when centred on physical characteristics by care organisations, theorists, and architects, have constrained our understanding of relationships to place within RACFs. Given that the concept of '*RACF as home*' has been held as an ideal for almost thirty years but a sense of home is yet to be achieved, a new way of thinking about RACFs is required. Rather than being limited by the definition of a residential building type, the RACF could be conceptualised as a place that supports some of the comforting practices of home and affords continuity and congruence with experiences of '*being-at-home*'. The concept of '*at-homeness*' as a particular aspect of well-being offers a more relevant and meaningful approach in both research and design, potentially more likely to create an environment where residents can develop a sense of place-identity and belonging.

## 8.2 Temporariness and belonging

Not only was the RACF rarely understood as ‘home’, but many residents also did not understand where they were in the world. Further to the issues of the RACF idealised as ‘home’, notionally a place of familiarity and security, is that the physical environment appears and feels like places of impermanence. The predominantly hospital-like environment suggests a place where one expects a relatively short stay. Some residents believed themselves to be in a guesthouse, a café, or a club. All are transient places, where one visits for a brief time before returning to the security and refuge of the family home and closely related familiar people.

Intensifying the residents’ sense of a fragile tenure is the multiple relocations to other RACFs and the hospital, as well as the lack of support within the environment for residents to anchor themselves or develop a sense of connection to self, others, or place. The institutional environment was inherently foreign, depersonalising, and disempowering, and the medical symbology was alienating. Residents’ expressions of fear and anxiety are threaded through their stories, most often to do with their inability to feel they have a place of belonging of the world-of-being-in-aged-care.

Thus, the RACF was experienced as a placeless place, where residents are unable to assign meaning to spaces and things, the basic premise of the way phenomenologists believe we experience and understand our reality or lifeworld. The unrecognisable and unfamiliar lifters and care aids described by Betty, as nameless ‘*white equipment*’ were disconcerting, but were regularly left in living areas and corridors. As a result, there is usually a significant disproportion between medical equipment and objects of everyday life, which is frequently due to insufficiently discrete and poorly located storage for the equipment necessary in a high-care unit. As an architect, I understand that in addition to medical equipment, the need for wheelchair accessibility and hygienic surfaces creates a challenge regarding efforts to soften the foreign and clinical feel of RACFs calling for more creative and innovative thinking by architects beyond a focus on functionality.



Figure 8.2 Living Room, Eplehagen Nursing Home, Sarpsborg, Norway. Designed for functionality and beauty. The doorway is wide to accommodate ease of circulation, and the floor materials are readily cleanable. The space is warm and welcoming space with domestic objects in context. There is spatial flexibility with the sliding door to divide or open the spaces. Domestic aesthetic outweighs the clinical need, i.e. walking frame and hygienic surfaces.

However, an outcome is that the physical environment of RACFs not only offers few clues for the residents to locate themselves, it often contains objects that residents cannot place in context and therefore, place themselves in the context. While Section 8.1 discussed the issues of the ‘*RACF as home*’, Longleaf had the added incongruence of the design elements of a hotel. Rather than achieving the goal of the briefing notes to be ‘*non-institutional*’, families described ‘*the bar thing*’ as a ‘*bit of a barrier.... I don’t know what I am I supposed to do?*’

The trend for the hotel model in RACF design is intended to remove institutional connotations associated with feared old age and to reassure relatives. Paradoxically, hotels are also transient

places, which one does not expect to feel like one's own while this study substantiates the deep-seated need for residents to feel that they belong.

Comparable with hotels and other spaces of a temporary stay, the living spaces of RACFs are typically neutral and conceptualised for a homogenous user-group without the memorabilia, photographs, keepsakes, and personal touches of a family living room.

The bland, pale tones with few patterns or colour contrast in Longleaf were not only unhelpful in assisting people with dementia to orient or anchor themselves in the building, the overly neutral decor ostensibly selected to appeal to everybody rendered the spaces meaningless and unplaceable. The lack of distinguishing characteristics or personalisation contributed to the sense of the RACF as a 'placeless space'.

The residents experienced the identical features and indistinct colouring of the bedrooms as even more challenging. The symbolism of 'beige neutrality' was that of an unspoken temporariness. The overly bland one-size fits all decor seemed based on an unacknowledged belief that residents may only be residing in the space for a relatively short period and that the next occupant is likely to have different needs and tastes.

While identical bedrooms are considered cost-effective to build, the constraints of a twelve-square metre room, typical in contemporary RACFs, means that residents must forfeit most of their possessions.

Research consensus is that room personalisation is highly beneficial and assumed by several researchers to be the norm, as well as desired by family and residents (Chaudhury 2008; Day et al. 2000). My taken-for-granted expectations that room customisation would be a normative practice in the RACF, however, was shown to be incorrect in several instances. Unexpectedly, the value of creating a sense of continuity with home and the self is often not understood by staff or the organisation, although this is not in keeping with notions of autonomy that are central to PCC discussed in Chapter 3.

Further, providing for personalisation had been overlooked during the design process with no mention in the brief or standard design guidelines. The bedrooms in Longleaf included little storage, wall space, or opportunity for the display of private items or furniture, and as a result, few rooms were personalised.

Notwithstanding the evidence and widely assumed advantages of personalisation, not all families and residents valued or wished to have their rooms customised. Betty did not want to accept Longleaf as her place of residence and believed that bringing in her belongings meant that she was not returning to her family home. Paula did not want the RACF associated with home and felt that Greg's belongings would be a sad and constant reminder that he was '*never coming home*' although she expressed a belief that personalisation would benefit him. Tom was more concerned that his bedroom was customised for his wife's comfort.

Generally, however, the residents without the defence of significant belongings experienced less moderation of the multiple losses resulting from placement. There was noticeably less connection with place for the residents in Longleaf with rooms that were minimally customised or not at all. Mary's expression of '*Room 12*' to describe her tenancy suggests a lack of ownership or connection with place, and Maree had no idea where she was.

While personalisation was relatively limited, the residents with access to the things they valued were more able to invoke a sense of belonging in the RACF. May's room was the most personalised, and



she was also the only participant who identified her room in Longleaf as home. Similarly, as she seemed to have some sense of control of her room and the customisation provides links to her identity, she appeared better able to maintain a stronger sense of self. This was also noticeable in the way the residents such as Joe could recall their past that was less apparent in those without meaningful personal belongings.

Joe's story demonstrated how his pictures of himself in his youth helped him to connect with his sense of self. This aligns with previous studies that have identified the benefits of reminiscence objects (Chaudhury 2003, 2008). This study begins to extend the idea to explore specific objects related to residents' previous homes to assist in retaining a sense of self, connection to the past, and an anchoring in place to develop. Compared to the other residents, May's daughter's conscious efforts to bring a '*little bit of home*' and '*some reality into her*' had seemed to help her mother identify her room as her own and to afford some sense of belonging in the RACF.

May's daughter also related that customising her mother's room had alleviated her guilt about admission and provided a sense of '*doing something good*'. The potential benefits of room personalisation for the family are vital but often overlooked in the literature. In Reuss et al. (2005) study, families felt that decorating the room to their relative's preference helped their family member settle more readily, but the organisation did not understand this.

Accepting that residents are unlikely to have the capacity to personalise their room, families who know their relative best could do so, providing clues to their personhood. Residents' belongings also had additional value imparting meaningful conversation cues for connecting with others, and notably in this study, a more effective way than expected to initiate and maintain social and research conversations with me.

Some family members thought room customisation would benefit their relative but had not done so. Rather than unwillingness, this was mostly due to uncertainty, and the lack of guidance and support from staff, in addition to perceived institutional or organisational restrictions.

Barriers such as the rules and lack of encouragement, and at times, active discouragement in making a room one's own, implied ownership of the room by the aged care organisation rather than the resident, reinforcing their sense of displacement. Not only did the uniformity of room design and standard décor further emphasise the transient nature of the spaces, but it also added to the sense of the RACF 'belonging' to the organisation.

Thus, while valuing autonomy and the individual are the stated goals of PCC and aged care organisations, it often does not extend to personal choice and control in residents' rooms. The personalisation of a place has been described as an inalienable right, the loss of which moulds individuals so that others may perceive them as a homogenous group and more easily managed (van der Horst 2004). Residents in RACFs often do not experience sovereignty even within their rooms and are limited in their ability to surround themselves with belongings that may help anchor their sense of self and belonging in place.

Adding to the residents' challenges in forming a place attachment is that the sense of security theoretically intended by the ideal of ageing-in-place, as discussed in Chapters 2 and 3, is not translating into practice. It was discouraging to observe that multiple relocations continue to occur between RACFs and the hospital.

Staff related that '*any kind of even little medical problem, then they get moved to a hospital, but we should do more here [Longleaf]*' (Molly, CSE, 12 July 2015). While transfers are often necessary for

acute medical treatment, there were occurrences of unnecessary relocations for conditions such as pneumonia, which Castle (2001) identifies as readily manageable within the RACF. While ageing-in-place implies a reasonably stable tenure, multiple transfers add to the residents' sense of being in a place of transition and experiences of dislocation, the opposite of the Heideggerian ideal of *'dwelling'*.

The benefits of co-location of RACFs with independent living units (ILUs), promoted through by-lines such as *'all your care needs will be met in one place'*, implies both ageing-in-place as well as a smooth transition for residents premised on familiarity. This tacit understanding seems based on the geographical proximity of buildings on the same site rather than any meaningful connection between the RACFs and those living more independently within The Village in ILUs.

Despite co-location, Marg, Maree, and Tom did not receive visits from Village residents. There appeared little social connection between The Village and the RACF, and Marg and Maree had no awareness that Longleaf was located on the same site. While arguably not knowing their location was notionally protective as Marg and Maree were not aware of their proximity to people who did not visit, they are likely to have been less lonely if their local friends and family were supported to spend more time with them.

In any case, there were no clear physical or social connections and each RACF The Village operated in isolation. The disconnection from The Village and the community exacerbated the residents' experience of separation and *'social death'* discussed in Chapter 3 and as well as the families' sense of being in an *'artificial world'*.

In my view, the primary benefit of co-location was the convenience for spouses visiting their relatives, and that some family members may have an on-site place to stay when their relatives are in their final days. In addition to cultural and management changes beyond the scope of this study, this suggests master-planning is required to provide site permeability with the community and a level of integration of the RACFs and ILU's on-site with a visual and spatial connection such as shared spaces to support the development of a community experience. Deliberately designed connections are required and families and residents in Longleaf would particularly have benefited if covered, accessible paths linked Longleaf with main café, gardens and parks in The Village.

In addition to the lack of connection with people outside the RACF, there was also the sense of separation from others within Longleaf. Other studies found that a frequently overlooked aspect of living within RACFs is that of co-existing with strangers, dissimilar to the family home. This study goes beyond the notion of accommodating relatively large numbers of unrelated people to identify additional alienating experiences. There is also the issue of ever-changing staff, as well as technicians, allied health consultants, pharmacists, funeral directors, and other families frequently coming and going from the RACF through what is ostensibly the residents' living room.

Although rarely noted in other research, both families and residents related feeling confronted daily by other visibly frail residents in the living space. The experience was distressing and alienating for residents and did not contribute to families *'feeling welcome'*. Several family and resident participants identified this issue as the main reason they chose not to use the dining room. The *'dining room residents'* however, seldom had a choice.



Figure 8.3 Living /dining, Eplehagen Nursing Home, Sarpsborg, Norway. They have interconnected living, dining and kitchen spaces that are similar to the family home. Staff can support residents to choose to dine in either space while being able to care for both groups simultaneously. While surfaces are readily cleanable, the colours are warm and vibrant, and the furniture and familiar objects placed in a manner that is cohesive and integrated with the spatial design typology.

The *'all or nothing'* spaces typical of RACFs are not conducive to social interaction with families, or between residents. In Longleaf, the bedrooms where *'nothing'* happened were isolating, and the dining room where *'everything and nothing'* happened was too noisy and distracting for meaningful conversations despite the research discussed in Chapter 3 of issues of people with dementia having an inability to filter unhelpful information and stimuli. Residents were often agitated in the space and people such as Jean, unable to focus on a conversation with her much loved daughter due to the multiple conversations taking place in the one room. Her daughter also related that the lack of privacy limited conversation topics.

Antonia wanted to connect with other residents in the dining room but was unable to. Greg only wanted to connect with his family but also spent the day in the dining room and explained that he slept to avoid others. Joe and May believed themselves to be unlike the other residents and kept themselves apart while at the same time, expressing feelings of loneliness. Large single spaces do not allow for the complexity of ways of connecting so that residents are strangely separate although surrounded by people. Enhanced social interaction has been verified when there is a choice of social spaces or larger bedrooms to accommodate family socialising (Young-Seon and Bosch 2013), yet large multi-purpose spaces remain typical in RACFs.

In addition to the lack of living space choice, there were also minimal links to outdoor spaces or the *'world'* beyond the walls of Longleaf. As overviewed in the background chapters, phenomenologists contend that a connection to the *'universe'* and nature provides a critical link to finding meaning in our lifeworld. For many residents in RACFs, the outdoors had been a significant part of their prior everyday life and self-identity. The forfeiture was experienced as a fragmentation from the world, usually associated with places of expected temporariness such as the hospital.

Residents often have little awareness of the weather, seasons, the day, or even time within the artificially lit and air-conditioned homogenised environment, as discussed in Chapter 5. In this way, residents are physically and temporally dislocated within an *'artificial environment'*. Despite having late-stage dementia, several residents in this study were able to articulate ongoing cognisance and associated distress resulting from their dislocation from the anchoring cycles of nature.

As outlined previously, there is minimal research but strong evidence for the therapeutic value of nature for people with mid-stage dementia. This study extends current knowledge demonstrating that those with late-stage dementia also benefit from, but often have limited access to, the outdoors. While many residents are immobile and gardening no longer viable, Betty's story showed several benefits of an outlook to a natural environment including a connection to her father and childhood memories, as well as affording everyday enjoyment and links to her pre-admission lifeworld.

Independent access to parks, raised garden beds or a planted deck is recommended within RACFs as well as views of nature from the bed and indoor sensory gardens. Mary's daughter, Mel suggested a large notice board in the dining room with the date, season, weather forecast, football score, and other simplified current affairs to facilitate better connection with the outside world. Although not referred to in the literature, information, and links to the '*outside world*' remained relevant for the residents despite their advanced dementia.

While the sense of disconnection from the '*outside world*', including the community, the retirement village, and nature, may imply that residents and families are '*insiders*' in the world-of-aged-care, the relationship was blurred and not straightforward. Instead, the alienating, clinical environment of RACFs where family and residents have unclear roles and do not '*feel welcome*', imbues an experience of being an '*outsider*', while at the same time they were sequestered in the RACF and removed from the outside world.

Admission to an RACF can feel like entering an alien world of unfamiliar medical language and a strange, unplaceable environment. Uncertain performative expectations intensified feelings of disconnection and '*outsider*'-status. Families in Longleaf were unsure if they were '*allowed through the gate*' of the nurses' station, permitted to use the Activities Room, or re-arrange furniture to appropriate a family space within the Dining Room.

While not intended as exclusionary, notions of spaces belonging to staff, and codes of behaviour determined by the organisation influenced families and residents to interpret that they were '*outsiders*'.

Families also experience the pervasive effects of dementia as they often spend many intense hours in the RACF over a prolonged period due to the trajectory of the disease. Families described being-in-the-world-of-aged-care as '*limbo land*' and as '*a whole other world in here*'.

The challenge of forming a connection with a place without a positive emotional response or understanding of a place was discussed in earlier chapters. Together with the foreign environment that is unrelatable to home and the inability and lack of assistance to anchor themselves in place or to feel that they belong in the RACF, experiences expressed by residents demonstrated profound awareness and deep grief despite their advanced cognitive impairment. Without an environment that supported the possibility to '*dwell*', the meaning residents made of Longleaf was that of what it was not; '*not home*', '*not welcoming*' and not a place they felt they belonged.

The findings relating to Longleaf are likely to be applicable in RACFs generally. The sense of being in a place of unacknowledged temporariness, with little within the environment to support anchoring oneself, profoundly impacted the residents' ability to connect with self, others, place, and the universe within the world-of-being-in-aged-care. Common to other RACFs is the unrecognisable medical equipment, neutral décor, identical bedrooms, and lack of connection to the community. '*Dwelling*' and '*connection*' were discussed in Chapter 3 as universal human needs and a foundation for wellbeing, shown in this study to remain significant and necessary regardless of advanced cognitive impairment or stage of life.

### 8.3 What matters and the unspoken

The residents' stories of experiences of homelessness or being in a place of temporariness within the world-of-being-in-aged-care are the antithesis of feelings of belonging and being-in-place. Some of the things that mattered most threaded through the residents' stories included a primal need to '*feel welcome*' and '*at-home*' and to maintain connection. Their stories conveyed experiences of

confusion, isolation, and alienation, lack of support to connect with the self, others, and the place they now find themselves, and grief for their many losses.

At a time when residents are losing connection with a sense of their self, they are admitted to an unplaceable place where it is challenging to form a sense of place-identity, connect with others, or feel that they belonged. The need for an RACF to *'feel welcoming'* was strongly highlighted by all participant groups. The findings point to the concept of *'feeling welcome'*, closely related to the phenomenological concept and basic human need to *'dwell'*, as elusive and complex, but essential to support meaning-making and anchoring within the RACF that token decorative gestures of home superimposed on the otherwise clinical milieu will not achieve.

Not only was family the residents' principle topic of conversation, but many also described their visits as *'the best part of the day'*. Greg and Tom were more concerned about their family's experience within the RACF than their own, which suggests a fear that their families will spend less time if they feel unwelcome.

While visiting is generally known to be beneficial, the length of time spent with a relative is likely to be helpful and influenced the quality of connection. More extended visits offer the potential to be present when residents have a *'good moment'*, that is an unpredictable and fluctuating time of reasonable cognition and communication capacity.

Whereas previous research has been focussed on people with early to mid-stage dementia, my project demonstrates that the need for connection to self and others remains meaningful for those in the final stages of life and crucial to be experienced as a part of the everyday-ness of being-in-the-world-of-aged-care. For most of the residents in this study, family visits were the only moments of pleasure reducing anxiety, loneliness, and boredom. Thus, a key goal of the RACF should be to find ways to extend those *'best times'*, adding further weight to the need for the RACF to *'feel welcoming'*. In this way, families may feel more supported to feel *'at-home'* so that they visit, spend time, and if they wish, can be involved in care.

Staff conveyed that some families start to withdraw following resident placement; a form of social death where people are treated *'as if dead'* as discussed in the background chapters. Residents demonstrated that they were profoundly cognisant of both the experience of social death and the need for the family to support their connection. Jean recognised that it was her daughter who *'keeps me connected to the world'*.

Unlike other studies, which focus on the needs of the family to improve visits for the benefit of the residents, my findings support a valuing of the needs of all in the care relationship. Several residents revealed a surprising ongoing need to care for others and were more concerned about the influence of the built environment on their family's wellbeing rather than having their own needs met. Greg was fretful that Longleaf was *'not an experience [good or welcoming] for the family'* and Tom did not require improvement of the environment for himself, rather he wanted *'things to be better here [in Longleaf] for my wife'*.

Although family members often remain engaged with their relatives following placement, several family participants expressed the view that visiting could, at times, be challenging. The medical setting as well as being in the presence of other frail, palliative residents primarily in the dining room was confronting and made some families feel uncomfortable. Families did not seem to have been considered in the building design and were not mentioned in the briefing notes. As Mel said, *'we should feel welcome here too. It's not that great for us, at all'*. Both family and staff identified the

need to make families feel welcome requiring essential facilities including a private discussion area, a choice of living rooms, and a dedicated family kitchen and lounge.

By providing family amenities in an ICU, Young-Seon and Bosch (2013) found that families would be inclined to stay longer and visit more frequently. While previous studies focused on the need to provide for families for the benefit of relatives, this study starts to uncover the personal needs of others in the reciprocal care triad. It was identified that dedicated family spaces could offer a place for families to connect with other families providing mutual support, *'lighter moments'*, and as a refuge to *'regather'* during intense times.

*'Feeling welcome'* was more complicated for families than just their own need for comfort in the RACF. They also need to believe that their resident feels a sense of belonging and is anchored in place and within themselves. Although participants were unable to articulate what *'feeling welcome'* meant, it is unlikely to be provided under the current objective drivers of design.

The drivers of design, in particular, the budget and focus on the functional needs of residents leading to small bedrooms, are particularly challenging in the later stages of a residents' life. I interpreted there to be an underlying assumption that bedrooms were predominantly for sleeping. Bedrooms in RACFs, however, are also spaces for dining, socialisation, and recreational activities, especially for *'bedroom residents'*. There is a compelling argument for bedrooms in RACFs to be considered as a private multi-purpose space. Larger bedrooms with sitting areas would provide a private place within the RACF to enable families to better connect with their relative especially in the later stages of life when most of the residents were bedridden, and their bedroom becomes a likely place of death, family vigils, and farewells.



Figure 8.4 Bedroom, Kloverhuset Hoeje Taastrup Nursing Home, Rugwytget, Denmark. The bedroom has been considered as more than a place to sleep and is sufficiently spacious to allow for guest seating and sleepovers. The space feels warm and welcoming with timber flooring, and familiar furnishings and objects. The photograph demonstrates how space can feel like home but be uncluttered for ease of access and care tasks. There is direct access to outside and opening windows to support resident choice.

McGann (2013) and Worpole (2009) proposed that providing single rooms contributes to the contemporary culture of dying alone and increases the risk of an undesired solitary death, which was reinforced by my findings. While Anderson (2013) observed that some residents were distressed by a neighbouring residents' dying process, other residents were comforted by the idea that they will have companionship when it was their turn. The staff participants who had worked in the previous nursing home with four-bed rooms supported this notion and engaged in a more nuanced discussion about single and shared rooms than families. They considered that the risk of loneliness and dying alone was increased in single rooms, especially for residents without family, and there was less opportunity for residents to watch out for each other. Other staff felt that families preferred single rooms so that they *'can say the private things that they need to say'*.

While single bedrooms are typical in Australian RACFs in contrast to earlier models with 4-bed shared rooms, this study evidenced that there were mixed outcomes for families and residents. Aligned

with studies by O'Connor and Tan (2012) and Chaudhury et al. (2005), a few staff, and residents felt that shared rooms could alleviate their loneliness. Some residents expressed a wish to have their spouse stay. However, families were unanimous in the need for single rooms, in contrast to families in Anderson's (2013) study who found comfort talking to other families in shared palliative care rooms.

Several staff suggested providing two-bed rooms in addition to single rooms to offer residents the option to share with their spouse or a compatible companion. Further to the mixed findings of the advantages and disadvantages of single or shared rooms, it is likely that needs for privacy, room personalisation, and sharing with others may change as residents' illness progresses. This study illustrates the complexity of this matter but reinforces the need for choice and flexibility including larger rooms, adjoining rooms, or movable dividing walls to reconfigure rooms as required, especially in the resident's final days.

Family presence usually became even more critical during a resident's last stages of life. Many families wish to keep vigil and care for their family member, but there was no accommodation in Longleaf, and insufficient space in the residents' rooms to sleep. Bedrooms with a layout to enable families to modify a residents' room into a peaceful and calming dying suite with additional chairs, soft furnishings, music, and appropriate adjustable lighting was not mentioned in the architect's briefing notes.

Death and dying were mostly disguised and unspoken topics within the world-of-being-of-aged-care generally. The subject has become normalised as a hidden discourse even within the RACF setting. Apparent in Longleaf was that a clear distinction was not made between the living and dying until a resident was euphemistically declared '*gone palliative*', similar to Froggatt's (2001) study. The dying were often only recognised in their final few days although predominantly from a biomedical or clinical perspective described by an RN as '*being when we start morphine*'.

A spatial consequence of having '*gone palliative*' was a further sequestering as dying residents are displaced from shared spaces to the relative isolation of their bedroom. Highlighted in this study was the tension between caring for the living and dying within the same place, made further challenging by the building design. While not implying that palliative residents should be in public areas, residents are frequently isolated in their rooms. The situation is less than ideal, with dying residents spending the majority of the time alone. One can only speculate on the existential suffering, especially as many, if not all are unlikely to comprehend that they are dying, and thus, the experience is that of fear and isolation.

There were also problematic instances where the layout did not support the residents to die in privacy. Residents were situated in the living spaces rather than their rooms when they could not be supervised from the nurses' office. While Chapter 3 identified that one of many people's deepest fears is dying alone, the design of standard RACFs with long corridors and layouts that do not support ease of supervision often leads to solitary deaths, despite widely accepted beliefs that people should not die alone.

Although the place of death is a crucial element in families' perception of a good death framing final memories of their loved one, this seems not to have been considered within the design. Many residents die alone in overly clinical RACF rooms or are transferred to hospital with lasting adverse effects on families, as this is often perceived to be a sub-optimal death.

Staff referred to Longleaf as the *'end of the line'*, implying a place to age and die-in-place. Thus, there was an underlying assumption that this meant dying in the RACF but over a third of the deaths that occurred during my research took place in the hospital.

Whereas the residents did not relate to Longleaf as their home, families considered it as a proxy residence. While dying in the family home is the expressed ideal of most Australians, the RACF became the most familiar and potentially anchoring place for residents over their final months. Although the RACF presented challenges in establishing a sense of belonging, it compared relatively more favourably than the even more foreign hospital environment.

The story in Chapter 7 of Mary's transfers due to pneumonia, eventual death in hospital, and family distress are relatively common. These deaths are argued to be the most upsetting of all (Abbey 1995; Abbey & Alzheimer's Australia 2013). While Mel had preferred her mother to die in the family home, she had reasonable expectations that the RACF was now *'home'*, implying her mother would die-in-place. However, her expectation was unmet, and she lamented that her mother's death *'wasn't supposed to be this way', 'not in a cold hospital'*. Especially distressing for Mel *'was not being there'*.

Several staff felt that the residents should be supported to die in the RACF, as it was *'their home now'*; facilitating *'continuity of care'* but building design and resourcing disenabled their ability to care for palliative residents. Two RNs suggested that a family suite positioned close to the central living area and nurses' office would allow both privacy for the family and resident while ensuring care and supervision could be afforded during the dying process. A window with a blind between the nurses' office and dying suite, and a door that people could choose to leave open to *'hear life'* would support a sense of remaining connected, and reduce solitary dying.

Despite the number of deaths occurring, the acknowledgement and discussion of dying were strangely lacking. It was often, however, paradoxically visible. The darkened room and open door exposing Richard's unconscious and close-to-death state were undisguised. Following death, the unusually closed door and *'Do not disturb'* sign, and body removal through the dining room was also incongruent with the silence about death.

In other studies, the majority of staff believed that the residents were unaware of the removal of bodies (Komaromy 2000; Tan et al. 2013). While not discussed directly with the residents, I observed that several were cognisant of the removal of Richard's body and visibly upset. Several staff expressed the view that the removal of bodies through the dining room was *'totally wrong'*. Almost half the staff confirmed that some residents were aware and distressed, and several believed that the problem was due to an oversight by the architects.

Regardless of commonly held beliefs that dead bodies should be hidden, this objective is often confounded by the spatial layout of RACFs, as well as by the ill-considered entrance design in Longleaf. A PCC valuing of the person and an extension of a good death is that a person's body should be treated with the same care and respect as living residents. In Longleaf, the undignified exit out the same door as the garbage and dirty laundry was powerfully symbolic and demonstrative of a general disconnection from the body as a person. While being in the presence of death and the dying is a relatively everyday experience for staff and desensitises people, body removal is more confronting for others in the care triad.

Although there are conflicting theories and evidence within the literature, about whether body removal should be concealed or not, a dignified exit from the RACF is a reasonable aim. As discussed in previous chapters, guidelines for death, dying, and dementia were missing from the design brief



for Longleaf and the standard RACF design guides and accreditation processes. Death and body removal are both an intricate architectural and philosophical issue, and it is likely that different aged care organisations will have different perspectives. However, a critical point of this study is that they are 'unspoken' which has led to many of the design problems.

#### 8.4 Discussion

While this a case study, I argue that typical Australian RACFs are currently subject to similar social, economic, and ideological forces. Predominantly objective knowledge and processes disconnected from the embodied and emotional lived experiences of being-in-the-world-of-aged-care produced Longleaf. In this way, the RACF became a place that is occupied, rather than a place to *'dwell'*.

At a time when people are losing a sense of connection with themselves, others and the world as a result of their illness, they are separated from their familiar world and placed in an environment that is further alienating and placeless. Amplified in this study, is that people with dementia are unsupported by the RACF environment to retain or rebuild their identity through an understanding of place and where they are in the world, a phenomenologically fundamental human need. Further, while their connection to self is reliant on others, with their family as the primary source of well-being, families also did not *'feel welcome'* in the RACF and had little sense of belonging.

This study provided a rare opportunity for participants to explore their experiences and how they made meaning of the RACF environment. While staff reflected that Longleaf was an *'artificial environment'* and based on a hospital-like model that was relatively unchanged since the 1980s, the families and residents focussed on what the RACF was *'not'*. For families and residents, Longleaf was *'not welcoming'*, and for the residents, it was *'not home'*. Widely held ideals of *'RACF as home'* juxtaposed against a focus on compliance, task efficiency, and risk minimisation seem only to manifest in a design solution which McIntyre and Harrison (2017) identified as a building that *'lies'*.

There is a mismatch between the focus and intentions of the design and resulting Longleaf built environment in relation to changing care needs and the quality of lived experiences as articulated in the stories in this study. Many people delay admission to the RACF until the later stages of dementia when rehabilitation, particularly with a view to increasing independence and lower care needs, is an impossible goal and death is relatively imminent. However, the conceptualisation of RACFs remains focused on *'fostering independence'* and an unrealistic model of restorative care.

The fear of falls and infection has contributed to a risk-averse environment eventuating in a hospital-like aesthetic as the normative paradigm, a default, rather than a deliberate design model. Risk minimisation and the need to maximise beds drives design and significantly contributes to the apparent lack of innovation by architects. As a result, the floor plan of typical RACFs such as Longleaf remains similar to those of the first purpose-built RACFs in the 1980s.

A disheartening picture emerges when we consider that while theoretically, the medical approach has become outmoded, and a shift towards a psychosocial model of care is widely accepted, the design of RACFs continues to reflect a clinical model of care. While I argued in Chapter 3, that PCC is not translating into practice, a similar biomedical and functional focus also objectifies and depersonalises the *'person'* in design. The *'resident'* in the design standards and briefing notes for Longleaf was reduced to conversations about circulation for wheelchairs and lifters, staff needs are focussed on their ability to deliver efficient care, and family needs often omitted altogether. In the way, the RACF little more than a place where the body of people with dementia is cared for while they are *'waiting to die'*.

The notion that people with dementia and the dying are deliberately removed from the 'public gaze' was discussed in Chapter 2. '*Terra incognita*', a term used by Brown, M (2003) to describe the hidden geography of the hospice, was found in this study to be equally applicable to RACFs. Similar to hospices, the RACF is also a place where people are sequestered from society and treated 'as if dead' before their biomedical death with associated experiences of loss of personhood, identity, and connection with the world.

Cultural sequestering of people with dementia and the dying partially explains the general lack of understanding by the community about the lived experiences of being-in-the-world-of-aged-care. As a result, a substantial proportion of the general population have had little exposure to death and have a limited understanding of dementia. Before commencing this study, I had given little thought to the experiences of RACF residents and understood dementia to be about memory loss despite my previous involvement in several large RACF architectural projects.

The institutionalisation of death and the dying described in Chapter 3 has de-normalised death so that it is now mostly a hidden experience. The world-of-being-in-aged-care was found in this study to have effectively become a veiled non-place, obscured from everyday consciousness. It was also evident that the challenging topics of death and dying are avoided even within Longleaf and by Aged Care Inc. despite their frequent occurrence.

The limited discourse and hidden nature of death, dying, and dementia within the community also offers a compelling explanation for the oversights in the briefing notes, design, and conceptualisation of Longleaf, as well as standard design guidelines and RACF accreditation processes resulting in the design of RACFs that are not fit-for-purpose.

The question that must be asked is that if RACFs are not understood as places to die so that architects are appropriately briefed, how can it be possible to have a 'good death' in the RACF? The architectural brief is usually considered the main 'text' in design forming the questions that precede the building, which is the 'answer' to the questions (Markus & Cameron 2002, p. 78). However, if questions remain unasked about dementia, death, and dying, then how can buildings respond appropriately?

A consequence of separating people with dementia and the dying from the living is that we know and understand little about who they are, their dreams, preferences, and desires for a good life, and by extension a 'good' death. It may be that a 'good death' is not easily definable and that individuals and families assign different meanings to death and dying.

Not only do we have little understanding, but we also seem as a community to give little, if any, consideration to the lived experiences of people with dementia, especially within the veiled world of the RACF. As supported by the findings of this study, it follows that we do not know how to provide supportive environments where people with dementia can die well.

Further, the use of euphemisms and other linguistic practices that disguise or deny RACFs as places of death prevent change. Komaromy (2000) points out that the first step is to recognise the reality of death and dying in RACFs to better support residents and their families. This requires conversations about death (Österlind et al. 2017). I argue that this view applies equally to the design of RACFs. Therapeutic environments are unlikely to be designed without recognition of the RACF as a hybrid place where people with dementia reside for their last months and where death is regularly encountered.

The duality of caring for both the living and dying sets RACFs apart from other healthcare settings. As discussed previously, hospitals focus on the living, providing clinical treatment and discharge, whereas hospices offer quality of life for the dying, although for comparatively short periods for generally younger people (Kayser-Jones et al. 2005; Parker 2011). It is the distinct identification of the role of the hospital and the hospice that supports an appropriate, integrated approach to design.

In contrast, there were multiple inconsistencies and contradictions in the conceptualisation of both the philosophy and the environment of Longleaf, typical in Australian RACFs. It was found that the role of the RACF was not clearly understood by designers, theorists, or RACF providers.

Although I have discussed issues of sequestration and social death, there is undeniably some clarity about the role of the hospice where the dying process is well-supported according to most reports (McGann 2013; Worpole 2009). Unlike the RACF, entering the hospice is usually with the knowledge by residents and family that it is the last building that they will inhabit and that death is imminent. Thus, the hospice environment has been designed and purpose-built with death and dying at the forefront of discussions and planning (McGann 2013; Saunders et al. 1981).

The hospice movement defines a good death as one that is marked by dignity, tranquillity, and comfort, respecting treatment preferences, and surrounded by family (McNamara 2001; Munn & Zimmerman 2006). While I commenced this study arguing that without research, we could not assume that the needs of people dying with late-stage dementia were the same as that of other groups, I found that most needs during death and dying are universal, and these goals are worthy of any place of death.

While the care manager described *'aged care as the new hospice'*, McGann (2013) suggests that there are lessons from the hospice model that could readily transfer to other healthcare settings. I agree that a direct transference of the hospice model to RACFs is not appropriate or recommended. The hospice model, however, could inform the discussions and design of RACFs.

In many ways, the RACF straddles the role of both hospice and hospital providing social and emotional support in addition to the clinical and functional care of significantly large numbers of people. Considerable nuancing of the hospice model is required to consider the requirements of residents for people who are at varying points along the prolonged and unpredictable trajectory to death, living and dying in one place.

As discussed previously, while hospices are generally designed for 5-12 patients, it seems likely that without changes to government policy, overly stringent standard building requirements, and the funding model of RACFs will result in the need for facilities with more than 60 beds for commercial viability. This further reinforces the need for the hospice model to inform rather than be applied as the design solution for RACFs.

Highlighted in this study is that the design response of *'homelike'* in the current superficial physical application has been unsuccessful in supporting residents to feel *'at-home'* in the RACF. Designing for people with late-stage dementia involves a complex set of issues, and there is no single answer. For some residents, the RACF as *'home'* is confusing and unsupported, for others, aspects of home such as the ability to appropriate space and make one's bedroom *'home'* can be supportive. Some residents benefit from room personalisation; others do not want belongings from home brought into the RACF.

A core design concept that emerged was the need for choice and flexibility to provide for individual residents' changing needs as their dementia symptoms progress from admission to likely death

within the RACF. Some residents may initially prefer a shared room but need a private room in the final stages of life. Other residents may prefer a private room and then a shared room as they draw closer to death. Many are likely to favour their own room for the duration of their residence.

A 'loose fit' building design with a flexible layout would allow individualisation of spaces, which together with a variety of living rooms discussed in Section 8.1 would support the ability to adjust spaces as necessary. Operable walls with consideration for acoustics would allow bedrooms to be shared or separated as required.

A further issue identified in Chapter 5 was the provision by the care organisation of indistinguishable furniture in each room and the fixed bedhead limiting the bed to one position in the bedroom. The bed is the most dominant object in the room, and thus all bedrooms were almost identical in layout. This limited the capacity to personalise rooms or rearrange the furniture. Ideally, bedrooms should be designed to accommodate at least two bed positions and additional personal furniture.



Figure 8.5 Bedroom, Krogholmgård Nursing Home, Vedbæk, Denmark. Hospital bed to facilitate care but less clinical than many models. Space in the bedroom for a personal desk to support residents' 'normal' activities and seating for guests. Vibrant colours. A view of nature, and direct access to the outdoors and opening windows to support resident choice.

Bedrooms need to be conceptualised as more than space for the residents to sleep. Larger rooms with layout flexibility would accommodate additional uses. In my estimation, bedrooms need to be a minimum of 18-20 square metres to allow for dining, recreational activities, and for family members or a spouse to stay overnight as requested by several residents. Provision of sufficient wall space for personal items including furniture, unfixed furniture, and permission to paint walls and doors different colours would support families to make the room a resident's own, rather than feeling like a homogenised, temporary space.

Essential learning from the hospice model is the potential for creating the bedroom as a refuge for the resident and family. Instead of being a temporary space, families could create a familiar and welcoming space to support the reliving of memories and family connections. It is my view that families should be allowed to screw into and paint walls. As an architect, I know this to take only a few hours to repair and is a relatively simple and cost-effective method of significantly changing the look and feel of a space. Room customisation should become the norm rather than the exception, which is likely to require organisational, cultural and policy changes as well as staff training to support families to tailor their relatives' room.

An important consideration is that rooms need to be bright, airy, and spacious, with warm, soft adjustable lighting, and a pleasant outlook including windows with a view and connection to nature so that the room *'feels welcoming'* whether families decorate or not.

For both residents and family, prioritising the quality of their bedroom as life-enhancing, and enriching is essential as it is the space that they are likely to spend most, if not all, of their time during their final days. Affording residents the ability to control daylight, lighting, music and noise as well as privacy and independence is an important design consideration. Bedrooms require sufficient

space to accommodate three or four visitors where at least one or two could sit near their loved one's head.

While I have discussed specific rooms, the most repeated requirement by participants was for the environment generally to '*feel welcoming*' and is, therefore, the most crucial consideration for design. As discussed in Section 8.3 however, '*feeling welcoming*' remains an elusive phenomenon to define within the RACF. The findings point to the loss of belongings, habits, and routines, practices of home and connections to others and the outside world as key aspects that disenable the residents' to '*feel welcome*'. The RACF needs to be conceived as a place that supports a continuity with the self, others, and the world beyond the current focus on functional requirements.

It is likely that certain clinical qualities in the RACF built environment are unavoidable due to residents' high care needs, but as Torrington et al. (2004) suggest about RACFs generally, this did not necessitate the hospital-like environment of Longleaf. Despite requiring care, the RACF was first and foremost, a place of residence and the medical aesthetic was strongly implicated in residents' confusion, and both theirs and their family's sense of feeling unwelcome. RACF building design needs to balance physical care with social and emotional needs to better support lived experiences and provide a more '*welcoming*' environment.

Chapter 2 and 3 described common sensory impairments experienced by people with dementia, but also acknowledged that researchers do not comprehensively understand sensory changes resulting from dementia (Chaudhury et al. 2017; Fleming et al. 2016; Ibrahim 2018). Despite their advanced dementia, the residents in this study added to our knowledge of the lived experiences of dementia and demonstrated a continuing complex sensory awareness and were able to articulate the lack of colour contrast, visual interest, pleasant aromas and tastes, and the challenging noisiness of the RACF related through their stories.

There is also a need for innovative and creative thinking beyond the limited palette of standard materials and neutral colours that continue to produce a clinical aesthetic and the current sensory deprivation. The full range of sensory experiences including textures, acoustics, tastes, smells, and passive as well as active visual interest requires consideration in the design. The use of warm, contrasting colours and natural materials including timber adds vibrancy to spaces and reduces the institutional characteristics of the built environment. Required items such as handrails can be cleverly designed to be functional and beautiful such as in the photographs over the page.



Figure 8.6 Clever handrail, Overspaarne Nursing Home, Haarlem, The Netherlands. An example of a handrail that is required by the building standards, functional and supports residents' mobility, doubles as a wheelchair strike plate but is beautiful.

The aspirations of the residents in Longleaf were not high. Residents wanted normalcy, which they related could be achieved through the enjoyment of a comforting hot drink with a loved one at a time of one's choosing, a cosy living room to dine privately with their family, or a bedroom with space for a sofa for visitors. Attention to facilities to support practices to bring small, everyday comforts will enhance daily lives. As Tom said, residents '*are not asking for much*'.

This study found that there was the potential to derive well-being through a focus on lived experiences including micro-spatial practices such as controlling a small corner within the building, the '*little things*' such as making a sandwich whenever desired, and room personalisation that borrows from the residents' individual meanings of home.

Evidenced in this study is that even people with late-stage dementia, such as Marg and Betty, continue to have agency and need some sense of control over their own lives, their choices and autonomy to support wellbeing. Providing opportunities within the environment for personal control, however, was not included in the brief or the resulting built environment.

In any case, many of the suggestions made by the participants were relatively inexpensive and straightforward but will significantly improve lived experiences and support an ability to '*dwell*'. While the environments of small-scale facilities, particularly the 'best practice' models described in Chapter 3, are often supportive of ordinary, everyday activities, larger RACFs usually are not. There also seems a widely accepted belief that these practices are less important for those with late-stage dementia, but this study demonstrates an ongoing need for practices of home, and to feel connected to place and to belong.

Overall, it seems that being-in-the-world-of-aged care; living, visiting, or working in RACFs is more endured than welcomed. The results of this study indicate that relocation into an RACF threatens a person with dementia's already fragile sense of self and connection to others and the world. There is an associated sense of loss of control over one's own life, inability to make choices, and uncertainty about expected behaviours in a place that they do not understand or feel that they belong.

Upon placement, residents need to reconstruct their sense of self and make meaning of their changed world but are unsupported to do so by the confusing temporariness, '*beige neutrality*', unrelatable spaces, and placelessness of the RACF built environment. They need support from others and the environment to place themselves and form a place attachment so that the RACF has a positive meaning in the context of their ongoing life. Typical RACFs, however, often appear as a fragmented set of some of the physical attributes of a putative home, a hospital, and in the case of Longleaf, also features of a hotel.

Residents did not recognise Longleaf as 'home' despite ideals and intentions of the architect and care organisation, and the inclusion of '*homelike*' objects and it seems that a more extensively applied home aesthetics is not the solution. These findings demonstrate that it is likely that the cultural hegemony of sight discussed in Chapter 3 has limited our understanding of home and a more wholistic approach based on embodied experiences and meaning-making is required.

'*Feeling welcome*' and '*at-home*' does not suggest a slavish borrowing nor an inauthentic mimicking of home but may be about creating a place with a focus on supporting the residents to feel '*at-home*'. It may be that the RACF does not need to be accepted as 'home' by the residents, rather it could be conceptualised to feel like the next best place, which includes some of the qualities that support residents to feel '*at-home*'. My findings show that belonging, connection, feeling in-place enhanced by providing a physical and social environment as close to a familiar, secure place as possible are more likely to promote a feeling of being '*welcome*'. What is needed is an embodiment

of the some of the qualities inherent to 'home' so that the RACF can become a place to ' *dwell* ' where family and residents are enabled in home-making practices tailored so that they feel ' *at-home* '.

It may be that for people with late-stage dementia and a high likelihood of a relatively short stay in an RACF, supporting them to retain fond memories of their previous family homes while developing a sense of belonging in the RACF may enhance wellbeing. A more honest design approach that honours and respects residents' awareness that then RACF is not home may be less confusing and more supportive.

The findings lead me to conclude that for real change to take place, a paradigm shift is required at the levels of policy and management and in the standard design guidelines as well as in design thinking. Rasmussen and Edvardsson (2007) suggest the notion of the hospice as a ' *lived retreat* ' offers a starting point in rethinking RACFs as it evokes a sense of a place to live well until death.

While Brown (2003) posits liminality in the hospice space as a negative, I argue that conceptualising the RACF as an ' *in-between* ' space as an opportunity. In this way, RACFs become a place to ' *dream* ' and reminisce and to connect with the self and others before leaving the world.

The role of the RACF needs to be conceptualised as a therapeutic place for people to experience the best life possible for their final weeks or months on their transitional path to death, and where they can be supported to die well. A new model may reduce the potential for design transference such as the superficial application of ' *homelike* ' features common in RACF design. While I have discussed the differences between an RACF and a hospice, and the problems associated with the concept of ' *home* ', the development of a new typology situating the RACF between the hospital, home, and hospice provides a hybrid space for the living and dying and supports all those in the care triad.

There may be some merit in borrowing from another typology such as the home or hospice but only when the implications for people living and dying with dementia, their families, and staff are comprehensively understood, and when the philosophy of care is clearly defined and then supported by the building design.

Although this study does not provide the answer to the best size, floor plan configuration, or design typology, it does demonstrate poorer lived experiences in larger contemporary RACFs. There is unlikely to be a single solution or design typology. While there was considerable overlap and similarities in the stories, there were also many differences between individual residents, family members, and staff, and even between participant groups, which indicates the need for community and site-specific designs with flexibility for individual and changing needs.

I posit that unless we can recreate a more holistic model for the ' *RACF as home* ', we are potentially doing people with dementia a disservice in trying to convince them it ' *is their home now* ' and this study makes obvious that we have underestimated their abilities to make meaning and be influenced by the design of the built environment. Notwithstanding the progression of their illness and inability to identify where they were, all of the residents in this study were deeply aware that they were ' *not home* ' and several actively refused to accept the ' *RACF as home* '. This raises the moral question of whether we should be continuing to push the metaphor or if would it be more integrous to start afresh with a new and different model.

Providing for the complex and unique requirements of those living and dying within the one place has been made more challenging by contemporary society's reluctance to face mortality and discuss the awkward topics of dementia and death. Ultimately, the architectural design of RACFs is linked to concepts of care and community attitudes towards people with dementia and the dying. Caring for

the living and dying presents a problematic balance but with sensitivity and innovative thinking free of the confines of '*RACF as home*' and '*non-institutional*' with a focus on supporting lived experiences, RACFs could be reconceptualised.

While other researchers have identified issues with the metaphor of '*RACF as home*', the need for personal belongings, and the importance of family for connection to self and for wellbeing, this study provides a more nuanced view through a hermeneutic phenomenological framework with collaboratively developed interpretations about lived experiences for people with dementia in the final stages of life. It reveals that fundamental human needs for personal choice and control, the need to '*feel welcome*' and a sense of belonging, and the need for connection to self, others, place and the world remains even while dying. These findings have implications for architectural practice, further research, and the future conceptualisation of RACFs reflected on in Chapter 9.



## CHAPTER 9: IMPLICATIONS FOR ARCHITECTURAL PRACTICE AND RESEARCH

The concluding chapter provides an opportunity to reflect on the aims of the study and the way forward for improving the design of RACFs.

This study aimed to explore the influence of the built environment on the lived experiences for people with dementia in their final stage of life, together with their family and staff, to improve the conceptualisation and design of RACFs. A hermeneutic phenomenological approach was employed to deepen understandings of how residents, families, and staff experience and make meaning of the RACF built environment. Through the development of collaborative interpretive stories, I hope to influence architectural practice and policy to provide improved outcomes for people with late-stage dementia, their family, and staff and inspire a rethinking of the way we design the RACF built environment.

Chapter 8 discussed interpretations of the participants' stories about Australian RACFs generally. The stories revealed the complex, and at times paradoxical, construction of RACFs as both home and hospital, in addition to their unspoken and often unacknowledged role as places to die. The RACF was experienced as a placeless place that did not support participants, especially residents', fundamental human need to connect with self, others, place, and the world.

Some of the interpretations discussed in Chapter 8 confirm, and others extend or contradict research where the focus has been on mid-stage dementia, and where people with dementia have not been directly included in the research. This project contributes to knowledge by adding to our depth of understandings of the world-of-being-in-aged-care through the perspective of lived experiences obtained by the direct involvement of people with late, rather than mid-stage dementia, their family, and staff. It demonstrates that while many of the needs of people with late-stage dementia are similar to those with mid-stage dementia, there is some nuancing mainly to do with immobility, higher dependency levels and more time spent in bedrooms, and the experiences of dying.

Whereas Chapter 8 offered recommendations for the overall conception and specific design solutions, Chapter 9 considers the implications for architectural practice and research.

Section 9.1 briefly explores ways to improve the RACF design process and policymaking. The benefits of a collaborative, reciprocal research approach in a natural setting, and the implications of involving people with dementia in research are discussed in Section 9.2. Section 9.3 outlines the study limitations and makes suggestions for future research. The thesis concludes with some final reflections.

### 9.1 Implications for architectural practice and policy

The over-prioritising of objective knowledge and design processes that had led to some of the issues discussed in Chapter 8, suggests the need to engage architects, managers, and policy-makers to develop better understandings of the implications of the built RACF environment for lived experiences.

The focus on operative requirements, hygiene, and risk management creates a clinical setting as a default, rather than a deliberate design. Attempts to 'de-institutionalise', typically with relatively token applications of domestic aesthetics, such as the floral curtains, residential scaled dining tables and the hotel bar in Longleaf, led to a fragmented and paradoxical set of physical attributes of home, hospital, and hotel.

The '*all or nothing*' spaces of the large, single, multi-purpose dining room, the identical and for the most part, unpersonalised bedrooms, the '*beige neutrality*' of the décor, the homogenised light and temperature, and disconnection from the outside world create a sense of temporariness—a placeless place that belongs to the organisation where the expectations of where and who one is, and how to behave or find everyday meaning is uncertain.

Rather than experiences of belonging or feeling '*at-home*', the residents in this study did not recognise or accept the '*RACF as home*'. They spent their days alone in their bedrooms or surrounded by others yet lonely and separate in the dining room, variously believing themselves to be in the hospital, a club-house or guest house; all places where one expects to stay a short time before returning to the family home. Clearly, this was not the intention of those that design and produce RACFs. However, without a deeper understanding of people's lived experiences, this practice is likely to continue.

This study begins to articulate how a more holistic and contextual understanding of person-environment interactions through understanding how residents, family, and staff experience and make meaning of RACF environments could complement objective knowledge and functional design approaches.

These stories reveal the complex, and at times paradoxical, construction of RACFs as both hospital and home, in addition to their unspoken and often unacknowledged role as places to die. I argue that rather than 'homes', RACFs need to be reconceptualised as hybrid places for the living and dying that anticipate and support the lived experiences of all those in the care triad. This requires the development of a new typology situated between the hospital, home and hospice and a paradigm shift in design thinking, practice, and policy aligned with the shifting landscape towards reciprocal models of care. Central to this transformation is recognition of the rights, value, and capacity of people with late-stage dementia to provide insights into their experiences of the world-of-being-in-aged-care.

Understanding and acknowledging the role of RACFs as places for dying has implications for the framing of mission and philosophy of care statements. New care statements will assist in providing a cohesive and integrated approach to understanding how the built environment will continue to support reciprocal relationship-based care provision while enhancing the lived and dying-in-place experiences in the RACF. A well-written, detailed brief that includes the organisations' care philosophy and vision for the experiences of residents, families, and staff may have provided essential information for the architects of Casuarina House.

The development of the design brief is a 'set of aspirations' and the crucial element in achieving buildings that meet the needs of all building users. The role of the architect is typically to understand and balance the needs of all building user groups (Markus and Cameron 2002). The ideal brief, however, should start by evoking an atmosphere, describing how a place should feel, and articulating a set of values before establishing the functional brief and more technical building requirements (Worpole 2009, p. 36).

The 'lived experience' of people with dementia should inform the briefing process and be the driver of RACF design, shifting the emphasis from the clinical care of a person with a disease to enhancing their everyday experiences. It may be useful to develop a briefing process that includes in-depth discussions about the potential everyday lived experiences of building users.

Adapting a briefing process described by (Worpole 2009, p. 34) for hospices, the RACF brief could consider the 'residents' journey' and that of their family from the drive into the grounds, and the first

glimpse of the resident's new room, through their daily experiences, and finally the pathway to death.

As most people in contemporary Western society are unlikely to have observed many deaths, in-depth consultation with staff may provide essential information and understandings about the experiences of the dying to be incorporated in the design. Staff in this study were the only participants who had been present for multiple deaths in Longleaf and able to talk about their experiences as a part of their everyday life. While further research is needed to understand what constitutes a 'good death' for people with late-stage dementia, the staff in this study were able to speak frankly about how they thought dying could be better provided for in the RACF.'

Consultation with staff and families would ideally include a 'walk through' of a typical day and set of resident, family, and staff experiences. As noted in Chapter 2, the majority of care organisations operate multiple RACFs, and conversations could take place with building users in relation to recently constructed facilities. This would also provide an opportunity for ongoing review and the potential for improvement in the absence or together with POEs.

Given many residents are immobile, in tub chairs and non-verbal, the brief needs to describe their high care needs and specific environmental requirements. Collaborative conversations in a naturalistic setting that is familiar and comfortable for each participant rather than a formal meeting or interview room and a feedback loop could provide an opportunity for a more inclusive briefing process and a discussion about the diversity of building users and need to provide flexibility and choice highlighted by this study.

Similarly, the need to consider diversity and the different ways that individuals and different user-groups use and experience spaces require inclusion in government policy and design guidelines. This may include including requirements within policy documents and standard design guidelines for architects and providers to develop or providing incentives to organisations to provide opportunities to personalise spaces and a choice of shared and private rooms.

Changes in government policy and standard design guidelines are required so that designing for subjective lived experiences, death, and dying are incorporated in the design process. Further research specific to late-stage dementia, death, and dying in RACFs is required, which must then be presented in a way that supports architects, policymakers, and managers to 'enter the world-of-being-in-aged-care'. Residents' journeys from admission to death, and a 'walk-through' building users typical days discussed above could be included in design guidelines. Stories were the primary tool in this study for creating a link between the reader and the participants' lifeworld. Potentially, a series of stories about a variety of people with dementia, family members, and staff could assist design. Stories could be appended to standard design guidelines or linked to appropriate web pages. Alternatively, resident, family, and staff quotes from research projects could be embedded in the standard guidelines.

Architects of RACFs have a responsibility that they may not always realise in designing a person's final place of residence. They need to bring higher aspirations to the design process that consider subjective wellbeing and how built spaces influence lived experiences and the meaning that people make about the environment beyond the current drivers of risk management and safety described in Chapter 3.

Architects need to push past their former understandings of RACFs previously conceived solutions. Several architects with a phenomenological underpinning to their work counsel that it is vital for architects to step back from their work and reflect on what they are doing and why they are doing it

(Coyne 2015; Harries 1997; Schön 1983; Snodgrass 1979). I would add that architects and managers should give further consideration to ‘who’ the RACF is being designed for, and to consider how people will ‘*dwell*’ rather than occupy abstract spaces.

As discussed in Chapter 3, the value of Post Occupancy Evaluations (POEs) is rarely recognised in RACF design processes. In my experience, and as substantiated in this study, organisations tend to appraise their buildings internally based on the experience of the CEO, and in some cases staff, rather than undertaking an independent assessment. This is a notable omission in light of the trend for increasingly larger aged care organisations to own multiple RACFs, and part of the reason the RACF design has remained remarkably unchanged for several decades. POEs offer the organisation the opportunity to evaluate the built environment, build upon successful design, and improve future RACFs.

## 9.2 Implications for research and involving people with dementia in research

A secondary aim of this study was to develop a sensitive research design that would enable the participation of people with cognitive and communication impairments, and thereby give them voice. Giving voice requires the development of a meaningful way to express the voice of people with late-stage dementia and to engage the reader, architects, and those involved in providing RACFs in the world-of-being-in-aged-care so that they may develop understandings of lived experiences and transfer that knowledge into other settings and situations.

This study engaged a unique combination of research qualities and methodologies, as well as a novel way of presenting research interpretations. While other researchers, mostly nurses, have engaged in care tasks and semi-structured conversations with some similarity to my volunteer work and prompted conversations, this study a 10-month immersion by an ‘*outsider*’, that is, an architect, specific to the built environment, and framed by hermeneutic phenomenology. Whereas most studies involve only the family or the staff and do not directly involve people with dementia, even those with early to mid-stage dementia, my project directly involves people with late-stage dementia, their families, and staff. Thus the interpretations were collaboratively developed rather than by the researcher as is most common.

Rather than one to five participants more common in a hermeneutic phenomenological approach, this study weaves together the voices of 31 participants. I decided to provide an overview of lived experiences and several wide-ranging issues of RACF built environments rather than a more in-depth interrogation of one or two points. Thus, I wove together thirty-one voices across four participant groups in stories. The stories are at once a means of giving voice to the participants, an interpretative tool, and a way to engage others in the world-of-being-in-aged-care.

While other researchers have avoided including people with dementia in research described in Chapter 4, the residents’ engagement in this study demonstrates that they can participate in meaningful research if naturalistic and individualised approaches are employed. Collaboration with the family and staff, together with the development of individual biographies, proved particularly helpful in trust building and customising research for each resident.

Without a careful research approach, time spent building rapport, and a gentle, conversational approach, it is unlikely that the profundity of responses and the scope of resident participation would have been achievable. Participants did not feel pressured by a sense of being in a ‘research situation’ enabling them to relax, and share their deepest anxieties, fears and profound insights that are less likely in strictly factual or quantitative study or traditional qualitative methodology with formal interviews where I would be more likely to be perceived as an ‘*outsider*’.

The immersive hermeneutic phenomenological approach blurred the lines of being an '*insider*' or an '*outsider*' and allowed me to build a relationship of trust enabling me to be sensitive to the residents' fluctuating cognition and well-being, the values held by staff and family, and normalising my presence supporting participants' natural behaviour and impromptu conversations. Rather than being a detached researcher, I was able to experience the rawness and authenticity of everyday life, provide real-time feedback to participants, and commence interpretation in the setting.

An essential aspect of a hermeneutic phenomenological approach is that interpretations are negotiated and situated which was assisted by the sensitive and true-to-life research approach. Undoubtedly, some resident responses were ambiguous, symbolic, and metaphorical with several interpretations possible. Consistent meaning-making is an unrealistic goal when involving people with dementia in research, but this was considered to add to the authenticity of the approach and informed my interpretations.

Residents were supported in both prompted and impromptu conversations by their personal belongings, in particular photographs of significant people and places. The objects were also essential to assist in building rapport with the residents. Unexpectedly, I also found sharing photos of my own family helpful in establishing research trust and familiarity, as well as an enjoyable topic of conversation for the residents. This finding reinforces the value of personal objects to enable people with dementia to retain a connection with the self and others but also demonstrates their value as a research tool for building relationships.

Attention to details, including consistency in my apparel, ensuring minimal distractions, and frequent, regular time spent with residents to maintain rapport, were crucial. Each resident responded to different items, physical cues within the environment, and even aspects of my attire on different days suggesting the need to provide as many cues as possible when involving people with dementia in research.

Resident participants exhibited profound awareness of complex emotions and the influence of the environment and were able to communicate the impact of the environment on the self and to relate deeply insightful interpretations of their current situation. Jean symbolically but accurately described her sense of feeling '*lost*'. Betty instinctively understood her limitations but exerted control over the corner she was able to manage. Both Tom and Antonia demonstrated an awareness of their imminent death, suggesting a general underestimation of the ability of people with late-stage dementia to process abstract concepts and discuss emotionally charged topics.

This study establishes the importance of employing conversational warm-ups and cool-downs, as well as the need for the researcher to share of themselves. I observed that residents were more able to engage in more extended interactions. This points to the need for flexibility and for a relaxed, conversational process that is allowed to unfold rather than attempting to force the research agenda.

The research was designed to honour and protect the participants, as well as facilitate their participation and ability to provide insight into the world-of-being-in-aged-care. While not intended to be therapeutic, several participants related that they had benefited from participating and expressed feeling appreciative that they had been given a voice that may help others, to have a better understanding of their situation. Participants generally responded positively to the methodological approach of hermeneutic looping and interpretation, and family and staff participants found the notion of multiple meanings and different perspectives engaging as well as helping them to make sense of their own lived experiences.

This project provides a case for the inclusion of people with late-stage dementia in appropriately and sensitively designed research. The study may also encourage future researchers to be inclusive and give Ethics Committees the confidence to approve research involving people with late-stage dementia in research.

These findings suggest that a true-to-life, relaxed approach reflecting an everyday conversation and individually tailored techniques together with a progressive and ongoing collaborative interpretative process for checking and collectively negotiating meanings are potentially useful for future research to further understand how the built environment can enhance lived experiences in RACFs and other healthcare settings.

### 9.3 Study limitations and future research

While this study focused on lived experiences in Australian RACFs, it also made clear the symbiotic relationship between people, philosophy of care, and building design that is often overlooked in research especially by non-architects.

As discussed in Chapter 3, with the majority of existing research on RACFs situated in the fields of nursing, gerontology and environmental psychology, there is limited understanding of the role that design and building procurement processes play in supporting the lived experiences of residents, their families and staff. Van Hoof et al. (2014) and Devlin and Arneill (2003) identified a gap between the world of researchers and the domain of design and construction, which may in part be due to the dearth of RACF research undertaken by architects. This study interrogated issues of compliance and design constraints, briefing processes and the design language engaged during briefing and how the focus on safety and functionality negatively impacted wellbeing and overlooked lived experiences. Further research is required, ideally with multi-disciplinary research teams, including architecture academics and practitioners.

The limitations of a single case study are that it is only one spatial configuration, organisational culture, and a specific demographic, making generalisation difficult. Consequently, comparative studies of RACFs with different types, sizes, and spatial configurations and layouts may be useful. While I agree with Torrington (2007) and Chaudhury et al. (2013) that a mixed method approach may afford additional knowledge, it is critical that people with dementia are directly involved.

Research to date for people with dementia has focussed on Dementia Care Units (DCUs) and identified small-scaled RACFs as best practice. Typical Australian RACFs, however, have over 60 beds with 50 to 80% of residents with a diagnosis of dementia. The efficacy of this model requires further research. Critically, research should explore how a sense of '*at-homeness*' can be achieved for people with dementia in larger RACFs.

Lived experiences and the impact of the built environment may have some variation between different types of dementia. While this was not apparent nor within the scope of this study, and research to date is about dementia generally, future researchers could investigate if people with specific dementia diagnoses such as Alzheimer's disease, vascular dementia, or Lewy Bodies have different environmental responses.

Longleaf was located in a relatively wealthy capital city suburb with the majority of residents having lived previously within a few suburbs of the RACF. Many had adult children and spouses living within visiting distance and family participants were among the most engaged families in the wing. Findings are likely to vary in rural and regional settings with different community demographics.

Future research should include more culturally diverse populations than the predominantly white Anglo-Saxon participants in this study. Further, notions such as being '*at-home*', as well as rituals of death and attitudes about ageing, dementia, and dying are likely to vary across different social demographics, nationalities and possibly gender.

Future studies may also consider exploring differences in lived experiences between typical and less typical RACFs, such as high-end or small, privately owned and government operated RACFs with diverse staffing ratios and organisational cultures.

This study was limited to 10 months with residents in the later stages of their illness and provided a general overview of the RACF. There is little understanding of the phenomenology of specific spaces such as the ideal bedroom for dying or lived experiences of bathrooms. Briefly discussed issues in this study such as territory, privacy, and room personalisation would benefit from more detailed research. Specific studies of the family needs and the benefits of accommodating them and different possibilities for supporting death and body removal would add to our understanding. This study identified that there are mixed views on the advantages of single and shared rooms and that needs may vary over time. Longitudinal studies about changing requirements from the point of admission up until death are suggested.

Although I have touched on concepts of a 'good death', due to the paucity of research about end-of-life experiences, it may even be that what constitutes a 'good death' differs in RACFs from other settings. Further research is required about death and dying experiences in RACFs including comparisons with the experiences of families when their relative is transferred to die in hospital. Including the perspective of bereaved families may provide insight into individual interpretations of 'good' deaths.

Each of the core phenomenological concepts of humans' fundamental need to '*dwell*', to feel that they belong and a sense of connectedness with self, others, place, and the world are briefly touched on in this overview study. Further studies that focus on each of these phenomenological concepts would provide deeper understandings.

While I have made recommendations for design improvements in Chapter 8, there was no scope in this project to incorporate and then assess before and after changes to the environment. Future interventionist research, including the improvements recommended in Chapter 8, would provide valuable comparative studies.

The similarity of the design of Longleaf to many typical RACFs that are relatively unchanged in concept since the 1980s suggests it was designed without consideration of current research or knowledge of 'best practice', changing community expectations and demographics, and other complexities and subtleties of designing for people with late-stage dementia. While Fleming et al. (2012) move some way towards understanding why dementia design principles are not applied in RACF design, further research about research translation is recommended. I agree with Sloane Devlin (2008) that architectural practitioners have difficulties accessing, and perhaps understanding, academic journals, suggesting that research findings need to be more accessible for the broader community.

## 9.4 Reflections

Edvardsson (2005) indicates that when people and places are as expected, they are not reflected on, and the ordinary is taken-for-granted. Similar to others in the community, I had given little thought to the world-of-being-in-aged-care prior to this study mostly because of the hidden nature of RACF within the community.

The experience of witnessing the challenges experienced by people with late-stage dementia, their families, and staff in the RACF was profoundly affecting. Undoubtedly, my world-view and understanding about lived experiences in aged care have been changed by the research. Initially, I viewed the situation through the 'lens of an architect', then became more research-oriented, before finally developing a more integrated perspective closer to that of an '*insider*' in the world-of-being-in-aged-care as the participants shared their stories of lived experiences with me.

For this, I owe a debt to my insightful participants who shared their inner world of understanding. I found their courage and generosity inspirational and humbling.

The importance of supporting lived experiences and feelings of being in place and '*at-home*' in RACFs beyond providing clinical care and a place where people are sheltered, fed, and their bodily needs met was a crucial finding in this study. The growing number of older people worldwide and the vulnerability of people living and dying with dementia in RACFs makes this quest essential.



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**APPENDIX 1: Ethics Application Extract including rationale and background for the project; Recruitment and consent procedures; and potential benefits, risks, and harms.**



## EXTRACT FROM ETHICS APPLICATION

### Qu. 9. Rationale and Background for the Project:

**Please give a plain English description of the aims of this study.**

The aim of this study is to provide an in-depth exploration of how the design of aged care homes enhances well-being by supporting caring relationship for residents living and dying with dementia, their family, and care staff.

Environmental research in this field to date has been largely empirical, focused on mid-stage dementia and managing behaviours and symptoms. There are few qualitative studies, minimal research on late-stage dementia, and almost no research by architects or from the perspective of people with dementia, their families, or staff carers. Without in-depth understanding of the lived experience of people dying with dementia or their carers, the reported dissatisfaction of Australian aged care homes design is likely to remain.

The objectives of this immersive case study are to:

1. Provide comprehensive, in-depth understanding about the lived experiences of people living and dying with dementia in a typically designed Australian aged care home, their family and care staff
2. Identify the gaps between the focus and intentions of best aged care home design practice and resulting buildings, and subjective well-being and optimal lived experiences of people living and dying with dementia, and their family and staff carers.
3. Explore how the design of aged care homes can better support quality ageing and dying-in-place, and well-being through caring relationships for residents living and dying with dementia, their family, and care staff.

**Please give a plain English description of the research justification for this study**

**Please include in-text citations within your justification.**

Driven by improved health care and reduced mortality rates, the population of Australians aged over 75 is set to increase from 6.4% in 2012 to 14.4% of the population in 2060, i.e. an increase of 4 million people (Aust. Government Prod. Commission 2013)

Living longer however, increases the likelihood of age-related diseases and disabilities, in particular dementia. It was estimated that approximately 171,200 Australians had dementia in 2000, increasing to 298 000 in 2012 and projected to exceed 730,000 by 2050 (Australian Institute of Health and Welfare 2012).

Dementia is a complex group of diseases of the brain characterised by deterioration of memory, orientation, comprehension, and language in the early stages progressing to immobility and inability to swallow food or breathe independently in the later stages leading to death (Abbey, 1995; Jacques and Jackson, 2000). Together with frequent co-morbidities, the level of care required in the later stages of the illness are beyond the skills and resources of most families. Despite familial promises, and public and government ideals of ageing-in-place, admission to a Residential Aged Care Facility (RACF) is often unavoidable.

It is estimated that up to 65% of care home residents have a diagnosis of dementia and a further 20% have a cognitive impairment (Aust. Government Prod. Commission, 2013; Alzheimer's Australia, 2010). This trend is set to continue and Australians are increasingly expected to die in an RACF (Aust. Government Prod. Commission 2011).

Given the above, it is reasonable for dementia and death to be considered core business for RACFs. Care facilities however, do not perceive themselves as a place for dying and customary goals are to maximise independence and improve health outcomes (Puurveen 2008). Reflected in this is that Australian RACF Design guidelines contain minimal reference to designing for moderate dementia only and no consideration of RACFs as a setting for late-stage dementia and death (Australian Dept. of Health and Ageing 2005; Queensland Government, 1999; Hunter and Elkington, 2005). Standard design guidelines for RACFs are compliance driven

and based on a medical model that is not congruent with current social discourse about person-centred care resulting in ongoing social stigma and built environments that have a negative impact on well-being.

The researcher's reading of over 400 peer-reviewed journal articles found that environmental research to date is largely empirical, focused on early to mid-stage dementia and managing behaviours and medical issues. There are few qualitative studies and minimal environmental research on late-stage dementia, dying-in-place or from the perspective of people with dementia or their carers.

Quality relationships with carers and remaining in a familiar environment have been identified within the researcher's literature review of environmental research as key elements to support well-being of people with dementia (Fleming and Purandare, 2010; Hadjri, Verity, & McManus, 2012). While relationships are considered the most important factor in determining quality of care and well-being for people with dementia (Nolan, Davies, & Brown, 2006), the literature review to date indicates the care relationship is primarily conceived through the concept of person-centred care (Kitwood 1997). This concept focuses on the benefits of the care relationship for the person with dementia, notionally rendering the carers' needs and well-being peripheral. The concept of well-being promoted by reciprocal care relationships expands the notion of person-centred care to include all of the people in the caring relationship: the person with dementia, the family, and staff carers. There are currently no known studies on how the design of the RACF built environment can enhance well-being by supporting reciprocal relationships.

An inclusive study equally values the needs and perspectives of all people within the care relationship and users of the building. A recent literature review by (Henning, Froggatt, & Keady, 2010) concluded that research generally into end of life and dying with dementia in RACFs and other healthcare settings from the family and carers' perspective is limited. There is little account taken of the views of people with dementia and their carers, little evidence that the design of RACFs are considered in terms of a setting for dying, and little evaluation of the building once it is in use (Rigby, Payne, & Froggatt, 2010; Mullin, Simpson, & Froggatt, 2013). Without qualitative or in-depth understanding of the lived experience of people dying with dementia or their carers, the reported dissatisfaction and sub-optimal lived experiences resulting from the design of RACFs is likely to remain.

## Qu. 10. Participants

Will the project involve any of the following participants? Please indicate how each of the following 'types of research participants' will be involved in the project.

		Primary intent of (or affected by) research	Possible coincidental recruitment	Design specifically excludes
(a) Pregnant Women?	(NS 4.1)	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
(b) Minors, i.e. children under 18 years of age?	(NS 4.2)	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
(c) People highly dependent on medical care who may be unable to give consent?	(NS 4.4)	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(d) People with a cognitive impairment, an intellectual disability, or mental illness?	(NS 4.5)	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(e) People who may be involved in illegal activities?	(NS 4.6)	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
(f) People in other countries?	(NS 4.8)	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
(g) Aboriginal and Torres Strait Islander peoples?	(NS 4.7)	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
(h) People who are identifiable by their membership of a cultural, ethnic or minority group?		<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

For each group identified as a "Primary intent of (or affected by) research", show how your research complies with the relevant chapter of the *National Statement*.

If you answered "Primary intent of (or affected by) research" to (g) you must also attach a statement indicating how Aboriginal and Torres Strait Islander sensitivities will be recognised (see the following for guidance: <http://www.nhmrc.gov.au/publications/synopses/e52syn.htm>)

### Primary intent of (or affected by) research-

#### People highly dependent on medical care who may be unable to give consent?

#### People with a cognitive impairment, an intellectual disability, or mental illness?

Residents living in a high care nursing home (RACF) will typically be elderly, likely to have high medical care needs, and have both communication and cognitive impairments. Traditional informed consent is unlikely to be achieved. The National Statement of Ethical Conduct in Human Research, 2007, updated March 2014 (The Statement) however, allows for tailored and thoughtfully designed non-traditional consent methods and several researchers have developed innovative proof of consent methods to address the issues. We have drawn upon these methods in the design of this study (See Section 15 Disclosure and Consent below).

Participation by RACF residents provide crucial insights into the lived experience that arguably cannot be described or conveyed by another. Without participation, their views remain unavailable. The study is focussed on the 'lived' experience and secondary information can only ever be partial and incomplete.

People who are aged, frail or have dementia or other forms of diminished cognitive capacity, potentially have increased susceptibility to discomfort/distress and the weighting of likely harm/benefit have been given substantial consideration in the study design (Dewing 2002 and 2007). Concerns regarding increased susceptibility to distress have been considered by taking all precautions possible to minimise discomfort and create a conversational situation in a familiar and comfortable environment. The researcher will complete research conversations with family and staff carers about individual normal communications methods, signs of fatigue, distress, or dissent (Dewing 2002 and 2007). In addition, a family or staff carer will be present at all interviews with residents.

Participants may leave any aspect of the study early (e.g. leave a focus group early), postpone or cease research conversations, or withdraw from the study altogether at any time if they wish, without acrimony and with no explanation necessary. Any sign of fatigue, distress, or dissent of the resident participants recognised by either the researcher, family member or staff carer present at the research conversations will be immediately acted on and the research conversations ceased, or the subject changed if appropriate.

In the eventuality that a participant becomes emotionally distressed, a registered nurse overseeing the care of the resident will be available to monitor the participant while the research conversations are occurring and to intercede should any signs of distress occur to minimise any potential long-term harm arising (See Section 17 - Intrusiveness and Section 18 – Potential benefits, risks, and harms).

Issues regarding consent will be dealt with by obtaining both written proxy consent from a guardian and verbal or non-verbal consent or assent from the resident participant (see Section 15 – Disclosure and consent).

The researchers acknowledge and affirm the right of people to have different values, beliefs, norms and aspirations, and therefore will treat all participants as equal, and will not discriminate according to membership of a cultural, ethnic or minority group, including Aboriginal and Torres Strait Islander peoples. The foundation of this study is based on the notion of reciprocal caring relationships where all people in the care triad are valued equally (Nolan, Ryan, Enderby & Reid, 2002). A similar notion applies in the research relationship

## **Recruitment of Participants**

### **How will participants be recruited? From where will your participants be recruited?**

#### **Give specific details about how participants will be recruited. Some questions to consider include:**

Recruitment will be in several stages using a progressive engagement and collaborative approach based on normal daily experiences and innovative approaches by other leading scholars in this field (Dewing, 2002 and 2007; Goodman et al. 2011; McKeown et al. 2010; McKillop and Wilkinson, 2004)

Progressive and ongoing consent achieved through this collaborative approach will be backed up with appropriate, tailored information and other required documentation.

The intention is to commence voluntary work and active field notes of residents, family, and care staff within the subject RACF wing for two to four weeks prior to seeking participant consent and commencing research conversations and semi-structured observations. Field note, photographs, and recordings of any nature will not be commenced of any research participants until formal consent to participate has been received. In addition to potentially providing the researcher with personal lived experiences of the built environment, working within the environment is also likely to provide an opportunity to build rapport and trust with the residents, family, and staff carers, helping to become familiar and break down potential researcher/ participant power relations.

By working within the environment, becoming familiar with residents, the researcher will be able to develop sensitive, tailored means of communication collaboratively with staff and family carers for each resident. Founded on an ethic of caring and values the needs, responsibilities and rights of all within the research relationship, a multi-faceted, collaborative approach enhances protection during research, minimises risks and alleviates many of the concerns of the family, staff, and care organisation (Beattie, 2009). The researcher will request the family, staff, and organisation to help select and guide communication with potential residents. A

direct recruiting approach by the researcher may not always be necessary, as the researcher will have spent time on the wing or unit prior to recruiting. In a recent Australian study adopting a similar approach to this study, potential participants were found to express curiosity about the researcher's presence, providing the researcher to discuss the study in an everyday conversational manner (Lee, 2010).

While staff will not be responsible for third party recruitment, they will be requested to assist the researcher to identify residents to be excluded due to health concerns. Staff will be familiar with both residents and family members and can assist the researcher to identify potentially appropriate family and resident participants to approach. Staff will also be requested to advise which residents have a cognitive impairment so that the researcher provides the appropriate Project Invitation, Information Sheet or Guide, and Consent forms to potential participants (See Appendices 2, 3, 8, 9, 14, and 15). Not only does this facilitate appropriate and sensitive communication, it helps to further reduce the risk of researcher/ participant power issues.

Several scholars have identified the potential for care staff bias when assisting to select potential participants (Chin, L 2010; Mullin, J., et al., 2013). The researcher will acknowledge the potential for bias in the results as the following may help to alleviate potential bias, but it is not possible to guarantee or prove 100% that there is no bias. Staff will be guiding rather than making the selection of participants and assisting the researcher by providing information about resident's relative cognitive capacity and state of well-being, and usual forms of communication as well as identifying potentially stressed family participants to exclude. The researcher will have worked voluntarily in the unit for some weeks prior to recruiting participants for observation, and prompted conversations assisting to build researcher rapport as well as some familiarity with the potential participants. In addition, the researcher will request assistance from several staff to curtail bias.

Another aspect of potential researcher/ participant power relations is that participants may feel an obligation to consent to participate as the researcher is working voluntarily in their resident wing. Staff, family, and resident participants will be assured that participation is entirely voluntary and refusal will be accepted by the researcher without acrimony or the need to supply an explanation. The voluntary nature of participation is reinforced on all Invitations, Project Information Sheets, and Consent Forms (See Appendices 2, 3, 4, 5, 6, 7, 8, 9, 10, 11, 12, 13, 14, 15, 16, 17, and 18).

Given the research methods proposed, it is essential that both the resident and their family carer be recruited. If the family member does not consent to participate, there is little point in attempting to recruit the resident.

Participants in Group 2- family carers and Group 3- staff carers will be invited verbally by the researcher to participate in a one-to-one prompted conversation and focus group discussion (*Appendices 4 and 5*). If a family carer expresses interest, they will be provided with a Project Information Sheet (*Appendix 10*), a participant consent form (*Appendix 17*) as well as a proxy resident consent form (*Appendix 16*) in person.

If a staff carer expresses interest, they will be provided with a Project Information sheet (*Appendix 11*) and a participant consent form (*Appendix 18*) which will be delivered in person or via email.

Resident participants will not be approached for recruitment and consent until Phase 2 of the research plan is complete. (See Section 13 - Procedures and Section 15 - Disclosure and Consent). Part one of conversations with family and staff carers is to develop a biography for each participant resident - their usual forms of verbal and non-verbal communication, assent, dissent, and consent in everyday practice. Research recruitment information and consent methods will then be developed, tailored to suit the needs of each individual resident (*Appendices 2, 3, 8, 9, 14 and 15*).

The intent of this project is to explore every-day lived experiences and thus it is appropriate that recruitment, consent, and research methods reflect normal, everyday activities within a familiar setting. This is particularly relevant for people with a cognitive impairment, as research has shown that capacity fluctuates and is situational, and that capability can be strengthened with support by others such as family and formal carers, as well as by a familiar environment (Hubbard, et al., 2003).

## **15. Disclosure and Consent**

**Does the project collect information from which individual participants can be identified? (NS 2.2)**

Yes ☒ No ☐

***If yes, could the research be conducted using non-identifiable information?***

Yes ☐ No ☒

Photographs are integral to the proposed research methods. Faces and facial expressions of people in the photographs are essential for prompted conversations about social relationships and lived experiences within the nursing home. It is possible that de-identification or blurring of faces in the photographs could confuse or upset people with a cognitive impairment. All research conversation and focus groups discussion transcripts, and field notes will be coded and de-identified.

**Does this project use any form of implicit or passive consent? (NS 2.2.5, 2.3)**

Yes ☐ No ☒

***If yes, please describe how your research complies with the relevant section of the *National Statement*.***

**Will there be any deception of participations including concealment and covert observation? (NS 2.3.1, 2.3.2)**

Yes ☐ No ☒

***If yes, please describe how your research complies with the relevant section of the *National Statement*.***

**Describe how participants will consent to participate in this study and how they will be informed of their rights (NS 2.2.1-2.2.7). Attach copies of your Information Sheet and Consent Form (where relevant) and give an explanation of the process by which you will obtain consent.**

Residents living in a high care home (RACF) will typically be elderly, likely to have a high medical care needs, and have both communication and cognitive impairments. Traditional informed consent is unlikely to be achieved. The Ethics Statement Section 2, Chapter 2.25 of the Statement provides for non-traditional consent methods such as 'oral expression' and 'conduct implying consent' providing they are appropriate (NHMRC et al. 2007b, p. 9). Processes have been developed that honour and protect the person, and that are sensitive and tailored to the needs of people with a cognitive impairment and/or have high medical care needs. The design of the consent processes below has drawn on several relevant and successful methods identified in other research that included people with a cognitive impairment.

Consent as an ongoing process is a widely accepted concept. Relatively self-explanatory terms used to describe ongoing consent processes include process consent (Dewing 2002, 2007) and progressive engagement (Robinson, Emden et al, 2011). McCormack (2002) designed a narrative-based approach to consent and Ashencaen Crabtree (2013) argues for a verbal consent process where the explanation becomes a conversation, and where the parameters are more adaptable between parties. These approaches are particularly relevant for people with dementia whose abilities and understanding can fluctuate.

Some of the obstacles to researching people with dementia may be overcome by collaboration with family and staff. Dewing (2007) and Nolan (2002) describe research methods that understand that capacity of people with dementia can be strengthened with support by others. In processes outlined by Dewing (2002) and Young and Manthorp (2009), a biography is sought from a family member or meaningful carer to identify and recognise individuals' usual signs of consent and assent, communication methods and meaning (McCormack, 2002). Assent is an important concept in dementia care can be adapted in research, allowing intent to be expressed even when verbal skills are diminished (Dewing, 2002, 2007; Hubbard, Downs et al. 2003). Young and Manthorp (2009) found the ability for non-verbal communication to persist well into the late stages of the disease progression. The researcher must understand the person's usual ways of communicating and support any decisions with detailed notes.

As the experience of cognitive impairment is unique to each individual, all research information and forms will be tailored and appropriately presented to potential participants (Appendices 2, 3, 7, 9, 14 and 15). For some people, slightly adapted written information is sufficient, for others a simple verbal invitation, explanation and consent recording rather than signature used (Appendices 14 and 15). Given that the capacity for verbal communication may be reduced, non-verbal and behavioural cues may be a suitable form of communication if reasonably understandable and clear (Dewing, 2002).

There is considerable literature demonstrating that even for those people with a severely impacted ability to recall actual events, experiences remain intact, and the emotional affect still felt by those same events and experiences (Hellström et al. 2007). Researchers have found the ability for non-verbal communication to persist well into the late stages of the disease progression. The focus of this study is lived experiences and appropriate for involvement of people with a cognitive impairment.

A multi-faceted and collaborative approach that includes all participants in the consent process will be used to enhance protection during research, minimise risks, and alleviate many of the concerns of the family, staff, and care organisation (Beattie, 2009). A biography will be sought for all residents that staff have identified as having a cognitive impairment, from a family member or meaningful carer to identify and recognise individuals' usual signs of consent and assent, communication methods and meaning. The researcher must understand the person's usual ways of communicating and support any decisions with detailed notes and evidence (Appendices 14 and 15).

An additional ethical and protective safeguard is to seek traditional proxy consent as an adjunct to the person with a cognitive impairments non-traditional consent (Appendix 16). The proxies' presence during research conversations with residents provides for additional monitoring for signs of distress and the need to cease or postpone research to minimise risk of psychological harm

**ONGOING CONSENT:** Consent will be an ongoing process with consent validation sought prior to each research participation occurrence for cognitively impaired participants in recognition of the issue of fluctuating and declining cognitive abilities of resident participant. Ongoing consent will be recorded for residents prior to each research conversation (Appendix 21).

The intention is to maximise the potential for inclusion but even when every care is taken, a person's assent or dissent may not be sufficiently clear to allow research involvement or adequately demonstrate consent (Ashencaen Crabtree, 2013). Should the researcher, family, or staff carer consider that consent of a resident participant has not been adequately communicated; the resident participant will be thanked for their interest but not included in the study.

**Group 2 Family and Group 3: Care Staff:** participants will be invited verbally during researcher volunteer shifts (Appendices 4 and 5). If interest in participating in the study is expressed, potential participants will be personally handed or emailed a Project Information Sheet (Appendices 10 and 11). Potential participants will be provided with contact details and an opportunity to ask questions and discuss any aspect of the study with the researcher. Upon request, participants will be provided with Consent Forms (Appendices 17 and 18) for their own participation and family participants will be provided with a Resident Proxy Consent Form (Appendix 16)

**Group 4 Participants:** The care home architect will be invited in writing (See Appendix 6). The care home manager will be invited in person (See Appendix 7). If interest in participating in the study is expressed, potential participants will be emailed or handed as appropriate a Project Information Sheet and Consent Form (Appendices 6, 12, 13 and 19). Potential participants will be provided with contact details and an opportunity to ask questions and discuss any aspect of the study with the researcher.

Ongoing consent will be checked prior to any research conversation and all participants reminded of their right to withdraw at any time without explanation or to withdraw consent to use photographs that include them in publications or presentations about the research.

## **18. Potential benefits, risks and harms (NS 2.1)**

## Participant(s)

This research will not provide a direct or measurable therapeutic benefit for resident, family and staff carer participants. This research does, however, provide the participants with an opportunity to describe their personal experiences and give their perspective about how the design of aged care homes that they live in, visit and work in impacts their relationships and their personal well-being to a wider audience. It has been argued that aged care residents, particularly those with a cognitive impairment, are one of the most under-researched groups within our community. There is also minimal research to date from the perspective of the family and staff carers.

Indirect therapeutic benefits may include a sense of inclusion for a group that often does not have a 'voice', a sense of positively contributing to research and that may improve the design for future care homes and the lives of others. The spirit of the research engagement is one of a collaborative approach where all involved are valued as equal conversation partners working together for a common goal to make things better for others (Nolan et al. 2002). Participants may feel valued and there may be some benefit in sharing their stories with an attentive listener.

The opportunity to share personal stories in a welcoming, familiar environment, supported by others has been shown to contribute to a strengthening of self-identity for residents that staff have identified as having a cognitive impairment (Hellström, I, et al. 2007).

**Organisation:** The research may provide insight into how residents, family and staff carers feel about or perceive a specific aged care environment. This may be of benefit when considering new aged care developments, renovations, or alterations. The researcher has agreed with the organisation to assist with architectural advice or suggestions for future design interventions if required.

At a practical level, by working voluntarily the researcher will provide companionship for residents, and their families and some assistance to care staff within a health care sector that is often under-resourced.

**Community:** Without in-depth understanding of the lived experience of people dying with dementia or their carers, the reported dissatisfaction of RACF design will remain. This research platform provides a perspective for people that are rarely heard. The study will provide a level of in-depth qualitative understanding that few if any architects have the resources to achieve in normal professional practice and has implications for improving design of future aged care facilities and educating future architects and providing a design resource for existing architects. There are also implications for policy and funding which are currently under review as our community starts to come to terms with the challenges of changing demographics, higher care needs, and community expectations that are currently unmet.

### (b) What are the possible risks or harms of this research to the participants? (NS 2.1)

Could your research evoke anxiety or lead to the recall of painful memories?	Yes	<input checked="" type="checkbox"/>	No	<input type="checkbox"/>
Will participants be asked to provide any information or commit any act, which might diminish self-respect or cause them to experience shame, embarrassment, or regret?	Yes	<input type="checkbox"/>	No	<input checked="" type="checkbox"/>
Will any procedure be used which may have an unpleasant or harmful side effect?	Yes	<input type="checkbox"/>	No	<input checked="" type="checkbox"/>
Does the research use any stimuli, tasks, or procedures, which may be experienced by subjects as stressful, noxious, or unpleasant? (NS 2.1)	Yes	<input type="checkbox"/>	No	<input checked="" type="checkbox"/>
Will you induce or create physical pain beyond mild discomfort?	Yes	<input type="checkbox"/>	No	<input checked="" type="checkbox"/>
Does your research explore potentially confidential business practices or seek to elicit potentially confidential commercial information from participants?	Yes	<input type="checkbox"/>	No	<input checked="" type="checkbox"/>



**Are there any other possible risks or harms of this research to the participants?**

Yes

☒

No

☐

***If yes, please list other possible risks or harms.***

**If you answered yes to any of the above, please describe how your research will comply with the National Statement (2.1). In addition, please describe the process (es) you will use to manage possible risks (e.g. if interviews may cause distress, provide details of support processes that will be put into place). If participants are to be referred to support services, contact details for these services must be included on the participant information sheet.**

**Resident participants-** It is acknowledged that conversations about lived experiences and personal relationships may sometimes trigger the recall of sad, distressing, or traumatic memories.

The research conversations do not require recall of facts or accurate reporting of events or lived experiences. The researcher will be particularly sensitive to word questions or prompts to reduce the risk of resident participants perceiving the conversation as a test of their memory capabilities, as this may cause embarrassment or anxiety and possibly emotional distress. Concerns regarding increased susceptibility to distress are addressed by taking all precautions possible to minimise discomfort and create a conversational situation in a familiar and comfortable environment. Every effort will be made to maintain a conversational approach and to keep the prompted conversation focused on personal stories and lived experiences, rather than the quality of the participant's memory. Personal stories are not required to be factually accurate.

A family member will be present at all staff identified cognitively impaired resident prompted conversations. While all questions will be in keeping with valuing the person and directed to the resident, the family member provides a safeguard and can cease, postpone or change the topic of the conversation if there is perceived to be an intrusion or resident distress.

A biography of each resident will be developed in conversation with staff and family members prior to commencing the prompted conversations with residents. This will facilitate a tailored means of communication including a list of potentially distressing topics to avoid and a personal understanding of each participant resident's usual signs of well and ill-being, or distress.

However, is possible that during conversations the recollection of memories and personal stories of lived experiences that are distressing to the resident participant may arise. If participants report or appear distressed by mentioning such information, the line of questioning will cease.

In addition to the participant having the option to cease or postpone a conversation, the researcher, family, and staff carers will also be monitoring the resident for any signs of ill-being. In the eventuality that a resident participant becomes emotionally distressed, a registered nurse overseeing the care of the resident will be available to monitor the participant while the interviews are occurring and to intercede should any signs of distress occur and provide debriefing and counselling to the participant.

A further risk is that in the length of time taken due to the part-time nature of the researcher's study, consenting frail and elderly research participants may suffer from deteriorating health, or die. The care staff and family will advise if conversations with individuals remain possible. As a further safeguard, prior to commencing each prompted conversation, the researcher will check the current health, fatigue, and general well-being of each resident at the time. Should the resident be asleep, being attended by a staff carer or in any way more than usually fatigued or unwell, the prompted conversation will be rescheduled. The researcher has built flexibility into the research design to accommodate these needs.

The researcher has given careful consideration to the issue of elder abuse and advice sought from the aged care organisation, supervisory team, and Professor Fran McNerney at UTASWDREC. In the unlikely event during the course of research, that elder abuse is reported to or suspected by the researcher, the following steps will be taken.

The first step is to immediately report to and seek advice from the supervisory team and the Professor of Ageing at Aged Care Inc.

Assaults are addressed under the Aged Care Act, 1997. The Australian Government has an Aged Care Complaint scheme in place that identifies reportable assaults and the subject aged care organisation is required by law to have documented procedures and staff education programs in place to deal with reportable assaults. It is compulsory for the researcher to report assaults even if the alleged or suspected assault occurred between family members or spouses.

If Aged Care Inc. receives an allegation that unreasonable use of force or unlawful sexual contact on a resident has taken place, they must report the allegation or suspicion as soon as reasonably practicable and within 24 hours to the Police and the Department via the Aged Care Complaints Scheme.

If the reported or suspected abuse is not an assault, but of a potentially minor nature, the researcher has a duty of care based on the principle of reasonableness to report to the Facility Manager and the supervisory team. Aged Care Inc. has an organisational protocol for the researcher to report to the resident's aged care Facility Manager. If the manager does not appear to be taking appropriate action or the abuse is within the subject unit, the researcher will then report to the Manager of Residential Care or the Deputy CEO of Aged Care Inc.

**Family Participants:** The prolonged and degenerative nature of dementia makes the context of care-giving complex and variable. Family carers are likely to experience long-term grief, including each time they notice a deterioration in their family resident's condition. Family members, particularly spouses, may themselves be elderly and frail. In order not to contribute to increased anxiety carers will be excluded from the study if staff identify that family members are under undue external stress.

There is the potential that talking about their experiences of caring for a family member who is frail, elderly and who may have a cognitive impairment may cause distress to some family participants. Should family carers exhibit any signs of distress or fatigue during prompted conversations; the researcher will gently change the subject or cease the conversation.

If any family participant becomes distressed during either the prompted conversations or focus group, they will be encouraged to contact the counselling service available through Alzheimer's Australia on 1800 100 500 or a registered nurse caring for their resident family member may provide debriefing and counselling to the participant.

Potential anxiety of family carers has been identified as a possible area of concern in other studies with participants expressing nervousness that potential complaints or negative reporting may impact adversely on the care of their family member living in the care homes. Family carers will be assured of identity confidentiality to alleviate this concern. Carers will be advised that they are free to withdraw from the study at any time should they have concerns.

Particular sensitivity by the researcher will be essential and assurances provided that research will have little if any impact on care provision or their time together with their resident family member. Prior to commencing each prompted conversation, the researcher will check if care tasks or other activities have been scheduled for the resident at the time with family and staff carers. If appropriate, the research conversation will be re-scheduled. Families are likely to have precious little time with the person with dementia and may be concerned that the research will impact on patient care or time with the family.

**Staff carers and the organisation:** Staff carers and the organisation may consider that care of residents will be impacted by the research. Every care will be taken so that the researcher fits in with the care home regime and there is minimal disruption to care or visits. The researcher has built in flexibility and will happily reschedule as required. Staff research questions have been minimised, as the researcher is mindful of time constraints within care organisations.

Staff carers may feel concerned that potential complaints or negative reporting may impact adversely on their employment in the care home or relationship with other staff. Staff carers will be assured of identity

confidentiality, and that this study in no way assesses or reports on their performance or quality of care provision to alleviate this concern. Staff will be advised that they are free to withdraw from the study at any time should they have concerns.

**All Participants:** Every effort will be made to minimise resident, family and staff carer participant burden. Travel is not required by any participants. The well-being and interests of the participants will be privileged over research outcomes. The researcher will converse with residents in their own rooms or if preferred, one of the small sitting nooks in the wing of the RACF. A familiar environment with minimum distractions is essential for people with a cognitive impairment as they have a considerably higher environmental sensitivity than other people do. The environment has been shown to assist capability and will serve as a cue in prompted conversations.

Conversations with family and staff carers will be held privately in an appropriate space within the subject unit or wing such as sitting nook, lounge, kitchen, or garden as preferred by the participant

Participants may leave any aspect of the study early (e.g. leave a focus group early), postpone or cease a research conversation, or withdraw from the study altogether at any time if they wish, without acrimony and with no explanation necessary. Any sign of fatigue, distress, or dissent of the resident participants recognised by either the researcher or family member present at the prompted conversation will be immediately acted on and the conversation ceased, or the subject changed if appropriate.

Privacy will be protected during observations. The researcher will not observe bathing, toileting, or medical care tasks.

While the focus of the research is about exploring the architecture of well-being for ageing, dementia, and dying-in-place, the researcher has been sensitive to the use of language to minimise distress for participants. The term 'dementia' will not be used directly with participants. Participants may be unaware of a dementia diagnosis, and if any reference is made at all to cognitive impairment, the more commonly used term 'memory issues' may be used. The researcher will not ask direct questions about dying-in-place as this may be distressing. The researcher intends to approach the topic of dying-in-place through the well-accepted notion of ageing-in-place.

This research platform study provides all participants with 'permission' or opportunity for talk, and there may be a benefit or at least usefulness in talking to someone especially an attentive, unhurried, and interested listener. Research conversations have not been designed to be purposefully therapeutic but are unlikely to cause distress, rather to provide an opportunity to 'unburden' or express the stresses of their lived experiences. Participants may find freedom in a non-judgemental and confidential environment that is not afforded in everyday life to many. The researcher has consciously designed research methods based on briefing and professional practices used in her daily work as an architect practitioner. She is both comfortable and experienced with these research methods and expects this will help participants to feel comfortable talking to her. In addition, the researcher will have been working within the care home for some months prior to commencing the research interviews allowing time to build trust and rapport with participants.

The opportunity to share thoughts and opinions, to have practical ideas and experiences validated, may contribute to a sense of well-being for all participants. Several studies that have included people with a cognitive impairment have found that if research is conducted in a safe context, it can be an enriching experience for all involved (Hellstrom, I et al 2007).

## **APPENDIX 2: Ethics application- Additional researcher statement**



**SCHOOL OF ARCHITECTURE AND DESIGN, & SCHOOL OF HEALTH SCIENCES,  
UNIVERSITY OF TASMANIA**

**RESEARCHER STATEMENT: ADDITIONAL INFORMATION**

**EXPLORING THE ARCHITECTURE OF WELL-BEING FOR DEMENTIA AND AGEING-IN-PLACE**

**Ethics Submission Preparation**

I understand the complexity and sensitivity of a research project that includes people with a cognitive impairment. The research proposed have been developed after thoroughly researching ethical issues and methods design including multiple qualitative studies by other researchers who had included people with a cognitive impairment, and who addressed sensitive and emotive topics.

I visited several potential aged care homes owned by four different organisations in Queensland and NSW to select the most appropriate aged care home and organisation for my study. I discussed potential research methods and each organisation's requirements with Care Managers at each site.

I corresponded with Katherine Shaw at HREC on several occasions and have incorporated her recommendations in my submission.

I have had detailed discussions with the proposed aged care organisation, Aged Care Inc. about my study design and have incorporated their recommendations into my research design.

**Potential Conflict of Interest**

All proposals for research with Aged Care Inc. are screened, provided with preliminary approval and co-ordinated by Professor X, [Professor of Ageing, University]. Accordingly, I sent my research plan, abstract and required documentation to her, resulting in both an in-principle approval for my PhD fieldwork and an unexpected job offer as Research Fellow with Aged Care Inc. and the [University].

I understand the potential for a perceived conflict of interest as I will be employed and paid by the same organisation in which I will be undertaking independent research.

To ensure independence, the following mechanisms have been put in place:

My research for my PhD and for my Research Fellowship, by mutual agreement, will be kept entirely separate. I believe that my judgement and PhD research and reporting will remain impartial. I have 22 years of professional architectural experience and the maturity and independence of thinking that will allow me to undertake both PhD fieldwork and Research Fellowship research without prejudice.

Other than the initial approval for my PhD fieldwork, Professor X will have no involvement in my study. We will discuss my project in any way. I will not report, provide written material such as PhD chapters, interview transcripts etc., to Professor X.

My current topic, proposed research design, and supervisory team have not been changed in order to accept the position at [the University]. All three of my supervisors, Dr Ceridwen Owen, Professor

Roger Fay, and Professor Andrew Robinson have provided approval and support for me to accept the Research Fellow position.

Co-ordination and future correspondence for my fieldwork will be with the Care Manager of the unit or wing at Aged Care Inc. where I will be undertaking my research as would have been the case for any other PhD candidate

All research data from my fieldwork will remain the property of UTAS. The only feedback and reporting I will undertake with Aged Care Inc. are as per the standard arrangements for any other PhD candidate.

### **Researcher Statement**

Prior to commencing my PhD, I had 22 years of professional experience as an architect. Eight years of that time was as the director of a company that specialised in sustainable and people-focussed design, more particularly, projects to support disabilities, dementia and ageing in place. A driving interest throughout my studies and career has been about how the design quality of the built environment can support and enhance well-being. Enrolling to do a PhD September 26, 2013 was largely motivated by a belief that I could make a positive difference in the lives of more people as a researcher and educator than by completing a small of architectural projects each year. My return to full-time study, however, has been far richer and more fulfilling than I expected, and I now consider research to be my calling.

The research methods I have designed are thoughtful, empathic and developed from the way I worked in my humanist architecture practice. My standard practice was to consult with and include all users of buildings in the briefing and design process including clients with physical, cognitive and communication impairments. I am experienced in talking and listening to people's stories and the way they make meaning and sense of the built environment.

My intention is that this research experience is enriching and rewarding for all involved.

**APPENDIX 3: Resident- Simplified invitation to participate, standard invitation to participate, simplified information sheet, standard information sheet, simplified consent to participate form, and standard consent to participate form**



**SCHOOL OF ARCHITECTURE & DESIGN, and SCHOOL OF HEALTH SCIENCES,  
UNIVERSITY OF TASMANIA**

**SIMPLIFIED INVITATION TO PARTICIPATE GUIDE (VERBAL): RESIDENT  
EXPLORING THE ARCHITECTURE OF WELL-BEING FOR AGEING-IN-PLACE**

You are invited to be part of a research project that is being undertaken by researchers at the University of Tasmania:

Dr Ceridwen Owen, Acting Head of School, Architecture & Design

Emeritus Prof Roger Fay, School of Architecture & Design

Prof Andrew Robinson, Co-Director, Wicking Dementia Research and Education Centre

Karen Kennedy, PhD Candidate, School of Architecture & Design

**This study about how the design of aged care homes can support well-being for residents, their family and care staff.**

This study is about finding ways to improve the design of aged care homes.

I, Karen Kennedy will be talking to you about how this room and building makes you feel. I will also be talking to your family and care staff about how the building feels to them.

I have been working here for a few weeks now, getting to know you and your family, and the people who care for you. I am going to be working here for a few more months as it helps me to learn about what it feels like to be working in an aged care home.

I will be taking photographs and talking to you, your family, and people that care for you. I would like to talk to you about what it feels like to live here. We might talk about some of the photographs I took. You can tell me stories about your life in Longleaf<sup>11</sup>.

Your relative (name) will sit with us while we talk. They are there to support you. They might just listen, or they might help you to remember things.

Later, if you wish, we can talk again. I'll talk to you about my thoughts about our conversation. You can change those things or tell me more.

I will record our talks using this (show device) if that is OK with you.

I want to hear about your life in Longleaf. I won't be writing reports or telling anyone about what your family or care staff do. I will be talking to other residents here too. Anything you tell me is private.

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<sup>11</sup> Pseudonyms have been used.



I'll come and talk to you in your room. If you don't feel well or don't feel like talking, that is OK. I can come back another time. If you change your mind and don't want to be a part of this study, that is OK too.

You could be helping me to improve the design of future aged care homes.

I can talk to you more about this study after you have had time to think about it. Please talk to (name relative) and care staff about it too. Next time I see you, I will talk about the study again and you can let me know what you think. I hope you will agree to talk with me, but it is OK for you to say no. This is all about you and your story. You can tell me about your life here if you wish.



**SCHOOL OF ARCHITECTURE & DESIGN, and SCHOOL OF HEALTH SCIENCES,  
UNIVERSITY OF TASMANIA**

**INVITATION TO PARTICIPATE GUIDE (VERBAL): RESIDENT  
EXPLORING THE ARCHITECTURE OF WELL-BEING FOR AGEING-IN-PLACE**

You are invited to be part of a research project that is being undertaken by researchers at the University of Tasmania:

Dr Ceridwen Owen, Acting Head of School, Architecture & Design

Emeritus Prof Roger Fay, School of Architecture & Design

Prof Andrew Robinson, Co-Director, Wicking Dementia Research and Education Centre

Karen Kennedy, PhD Candidate, School of Architecture & Design

**This PhD research project is about the architecture of well-being for ageing-in-place.**

The aim of this study is to provide an in-depth exploration of how design of aged care homes enhances well-being by supporting caring relationship for residents, their family, and care staff.

I, Karen Kennedy, have been and will continue to work voluntarily for some months in your care home, Longleaf. This has allowed me time to experience the built environment, build rapport with residents, family and staff, and to provide an opportunity for considerable observation time and research conversations allowing me to develop an in-depth understanding of life in an aged care home.

This research explores how the design of nursing homes could better support quality ageing-in-place. It explores the ways in which the built environment can enhance well-being by supporting the care relationships of residents, their families, and care staff.

The study involves engaging in everyday conversations and observations of interactions between residents and their families, and care staff in the Aged Care Inc. home. I will take photographs focussing on how the design of aged care homes supports residents, family, and staff carer's relationships. If you choose to participate, you will be involved in a one-to-one conversational style interview with me of approximately 45 to 60-minute duration.

The conversation will be about you, your story, and experiences of living in (care home name). We can discuss the photographs I took and your personal experiences of how the environment does or doesn't support you and your relationships with your family and carer staff. You will have an opportunity to talk about your thoughts on the design of Longleaf, what you like about it, and if there is anything you think could be improved and finally to make suggestions about what you would do to make it a better place.

Your relative (name) will sit in on the conversation. They are there to support you. They might just listen, or they might help you to remember things.

Later, you can choose to be involved in a second similar style research conversation to talk about my interpretations and my research, or to add to or change anything from the previous conversation if you wish.

The research conversations will be audio recorded.

Please be assured the research is in no way about assessing, making judgement, or reporting on performance of Aged care Inc. you or your family, or the quality of care received. The study will have no impact on your care or time with your family. Anything you say will be confidential and not reported to the staff or organisation. Your identity and personal information will be treated with utmost respect and remain confidential. The conversational interviews will be held in your room or another part of the care home that suits you.

This study seeks a deeper understanding of the influence of the aged care home building design on well-being from the perspective of residents, their family and staff carers.

It is unlikely that this study will lead to changes to the design of your present care home, but you may be helping to make a positive difference to the lives of other people in aged care homes in the future. It also gives you a chance to tell your story.

The study has implications for developing strategies to improve the design of aged care homes design, policy, design guidelines, and funding. The outcomes are intended to educate future architects, and to provide comprehensive, qualitative information about lived experiences of people within an aged care home that are often not available otherwise.

If you are interested in being involved, have a think about it, discuss it with your relative (name), family and friends, and please let me, Karen Kennedy know the next time you see me in Longleaf and I will provide you with a Project Information Sheet and a Consent to Participate form. I am happy to answer any questions and discuss the study in more detail at any time.

Once I have received your consent, I will contact you to arrange a time and place that best suits you for the conversational interview. I understand that there are a lot of demands on your time and have designed this study to have minimal impact on you and your time with (relatives name).

If you have concerns about any aspect of this study, you may contact the Chief Investigator Dr Ceridwen Owen (UTAS School of Architecture and Design, telephone. 03 6324 4479) or Professor Andrew Robinson (Wicking Dementia Research and Education Centre, UTAS, telephone. 03 6226 473) to discuss this further.



**SCHOOL OF ARCHITECTURE & DESIGN, and SCHOOL OF HEALTH SCIENCES,  
UNIVERSITY OF TASMANIA**

**SIMPLIFIED PROJECT INFORMATION GUIDE (VERBAL): RESIDENT**

**EXPLORING THE ARCHITECTURE OF WELL-BEING FOR AGEING-IN-PLACE** Good morning/ afternoon name) Thank you for taking time to talk to me. Your story is important to me.

**(Invitation)** You are invited to be involved in my study about how the design of aged care homes can enhance your well-being by supporting your caring relationships with your family and care staff. My name is Karen and I am doing a study about finding ways to make the design of aged care homes better for everybody.

**1. Purpose** I will be talking to you about how this room and other spaces here make you feel. I will also be talking to your family and care staff about how your care home feels to them.

More experienced researchers will be helping me and checking what I do. Their names are Dr Ceridwen Owen, and Professor Andrew Robinson. They are both from the University of Tasmania.

**2. Why have I been invited?** I would like to talk to you, because you know your own room and this wing better than anyone else does and you are the best person to tell me about how the building and garden makes you feel.

**3. What does the study involve?** I have been working here for a few weeks now, getting to know you and your family, and the people caring for you. I am going to be working here for a few more months as it helps me to learn about what it feels like to work in an aged care home.

I will be taking photographs and talking to you, your family, and people caring for you. I would like to talk to you about what it feels like to live here. We might talk about some of the photographs I took. You can tell me stories about your life here Longleaf

Your relative (name) will sit with us while we talk. They are there to support you. They might simply listen, or they might help you to remember things.

Later, if you wish, we can talk again. I'll talk to you about what I have been thinking about the things you told me. You can make changes or tell me more if you wish.

If it is OK with you, I will record our conversations using this (show device).

I want to hear about your life here in Longleaf. I won't be writing reports or telling anyone about what your family or care staff do. I will also be talking to other residents. Anything you tell me is private.

I'll come and talk to you in your room. It is OK to say no, if you don't feel well or don't feel like talking. I can come back another time. If you change your mind and don't want to be a part of this study, that is OK too.

**4. Benefits** You might enjoy telling me about your life. You could be helping me to help make aged care homes better for other people in the future.

**5. Risks** Sometimes, talking can trigger memories that might be upsetting. If your nurse, your (name relative) or I think you are starting to get upset, the conversation will be changed to something easier or stopped. You can also choose to stop the conversation anytime you want.

**6. Privacy** Anything you tell me will be kept private. I won't use your real name or let anyone know where you live. You or (name relative) can choose another name for me to use when I write or talk in public.

All your information will be kept safe. Except for reports, all your information will be destroyed 5 years after the last report is published.

You can change your mind and say no to the use of your photographs at any time during the study and I won't use them. I can also provide a copy of the typed transcript of your research conversation for you to check if you wish. This cannot happen if the paper has been published or presentation already happened.

**7. Questions** I am happy to answer your questions whenever I see you here Longleaf.

I can talk to you more about this study after you have had time to think about it. Please talk to (name relative) and care staff about it too.

Aged care Inc. and the University Ethics Committee have approved my study and checked that I am doing it well. My supervisors, Dr Ceridwen Owen and Professor Robinson have also checked my study.

You can talk to your Care Manager (name) to make sure, if you wish.

**8. Do I have to take part in this study?**

It is completely OK for you to say no. This is all about you and your story. You can tell me about your life here if you wish. You can stop anytime you wish.

Next time I see you, I will talk to you about the study again and you can let me know if you want to be involved.

If the answer is no, that is perfectly fine. If it is yes, then I will ask (name relative) to come to your room and we will fill out a short form for you that says you are happy to be included.

**Thank you for taking time to listen to me today.**



**SCHOOL OF ARCHITECTURE & DESIGN, and SCHOOL OF HEALTH SCIENCES,  
UNIVERSITY OF TASMANIA**

**PROJECT INFORMATION SHEET: RESIDENT**

**EXPLORING THE ARCHITECTURE OF WELL-BEING FOR AGEING-IN-PLACE**

The views of residents in care homes are very important to us. Thank you for taking time to read this Project Information Sheet.

**Invitation**

You are invited to participate in a PhD research study about the architecture of well-being for ageing-in-place, exploring how the design of aged care homes can enhance well-being through the support of caring relationships for residents, their families, and staff carers.

The study is being conducted by:

Karen Kennedy, Architect and PhD Candidate, School of Architecture & Design, and the School of Health Sciences, University of Tasmania

Dr Ceridwen Owen, School of Architecture & Design, University of Tasmania

Professor Andrew Robinson, Wicking Dementia Research and Education Centre, University of Tasmania

Emeritus Professor Roger Fay, School of Architecture & Design, University of Tasmania

**1. What is the purpose of this study?**

The aim of the study is to provide a comprehensive, in-depth understanding about the lived experiences of people living in a typical Australian aged care home, and their family and staff carers. This study explores how the design of aged care homes could be improved to support quality ageing in place, and the well-being of everybody in the care relationship.

**2. Why have I been invited to participate in this study?**

You have been invited to participate because you are a resident of Longleaf and you have first-hand experience of how the design of Longleaf affects your sense of well-being, your family's sense of well-being and how it supports or otherwise your relationships with your family and care staff.

**3. What does the study involve?**

The study involves the researcher working voluntarily in Longleaf, assisting with day-to-day care tasks to become immersed in the lives of people living and working in a typical Australian aged care home. This will help to build rapport and familiarity with residents, family, and care staff, and to provide the researcher with a sense of their lived experiences.

Over a period of several months, the researcher will be engaging in everyday conversations and observations of interactions between residents, and their families and care staff in the Aged care Inc. home. The researcher will take photographs focussing on how the building design supports residents, family, and care staff relationships. The study includes one-to-one conversational style interviews with residents, their families, and care staff to talk about the photos, their experiences of

life in Longleaf, how the design of the building enhances their well-being and supports their relationships.

In addition, the researcher will also be analysing the architectural brief and drawings and engaging in a conversation with both the architect and care manager of Longleaf about the focus and intentions of the design and the resulting building.

If you choose to participate, you will be involved a conversational style interview with the researcher of approximately 45 to 60-minute duration. During the research conversation, we will select your preferred photos and you will be asked whether you are happy for the photos to be used in research publications about the study or conference presentations. You do not have to consent for any photos to be used this way. You can still participate in the research conversation (s) even if you don't want photos to be used in publications or presentations.

The conversation will be about your personal experiences of how the environment does or does not support you and your relationships with your family and care staff. You will have an opportunity to talk about your thoughts on the design of Longleaf, what you like about it and if you think it needs improving, and finally to make suggestions about how it could be improved.

Your relative (name) will be sitting in on the research conversations. They may simply listen in, or if appropriate help you to remember things or let the researcher know if they think it is time to stop the conversation or change the subject because you are getting tired, feel unwell or unhappy. You can also stop or postpone the conversation anytime you wish without explaining why. A month or so after the first conversation, you can choose to be involved in a second similar style research conversation to talk about the researcher's interpretations. You can add to or change anything from the first conversation if you wish. (Relatives name) will also be present at this research conversation too.

The research conversations will be audio recorded and typed up word-for-word to be used for analysis and interpretation by the researcher. The researcher is happy to provide you with a copy of the transcript of your research conversation at your request for you to check, and if you wish, you may amend.

Please be assured the research is in no way about assessing, making judgement, or reporting on the performance of Aged Care Inc., you or your family, or the quality of care received. The study will have no impact on your care and anything you say will be confidential and not reported to the staff or the organisation. Your identity and personal information will be treated with utmost respect and remain confidential. The conversational interviews will be held in your room, unless you prefer another place in Longleaf.

#### **4. Are there possible benefits from participation in this study?**

This is an opportunity to collaborate with the researcher/architect so that a more comprehensive understanding of the experiences of residents, families, and care staff in Australian aged care homes can be gained. The aim of the research is to improve the design of future aged care homes so that residents, family, and care staff relationships are supported, and their well-being enhanced.

It is unlikely that this study will lead to changes to the design of your present care home or your room, but you may be helping to make a positive difference to the lives of other people in aged care homes in the future. While the study is not intended to be therapeutic, you might find it beneficial to have a chance to tell your story to someone who is very interested in what you have to say. Taking part in the study should be an interesting and rewarding experience and participants in similar studies have reported the experience as very positive.

The study has implications for developing strategies to improve future Australian aged care home design, policy, design guidelines, and funding. The outcomes are intended to educate future architects, and to provide comprehensive, qualitative information about the lived experiences of people within an Australian aged care home that are often not available otherwise.

#### **5. Are there any disadvantages or risks in taking part in the study?**

Sometimes talking about your personal experiences can trigger memories that can be upsetting. The researcher is very sensitive and will be careful in research conversations, but if you become upset, the researcher and your family will know to change the topic, or to postpone or cancel the research conversation. One of your nurses will also periodically monitor the conversation and will intercede if appropriate and make sure that you are well.

There is also a chance someone could recognise you or your relative from the photos. That is why we ask you to select and approve of photographs for use in publications and presentation.

#### **6. How will my information be kept private?**

All information will be treated with respect and confidentiality, and your name, your relative's name, the name of your care home and location, or any other identifying information will not be used in publications about the research. When we write the research report and any publications or give presentations, we may use some of the phrases you have said, but they will not be identifiable, as we will only ever use the pseudonym that you chose for yourself.

The research and focus group audio recordings and transcripts will be kept in a secure location on the University of Tasmania password protected server and on a password protected computer in the remotely located secured home of the researcher. All electronic data will be deleted 5 years after study findings have been published.

If you give permission to use photographs of you, or transcripts of your research conversations and afterwards change your mind, you can contact Karen Kennedy, and they will be removed from any papers or presentations. Please note that this cannot happen if the paper has been published or presentation already happened.

#### **7. What if I have questions about this study?**

Karen is happy to answer any questions or concerns and discuss the study in more detail at any time either in Longleaf or you can phone her mobile 04.....

The Chief Investigator Dr Ceridwen Owen (UTAS School of Architecture and Design, telephone. 03 6324 4479) or Professor Andrew Robinson (Wicking Dementia Research and Education Centre, UTAS, telephone. 03 6226 473) are overseeing this project to ensure it is a high-quality study. You may also discuss concerns or questions about this study with them.

Aged care Inc. has kindly provided approval and supports this study.

This study has been approved by the Tasmanian Social Science Research Ethics Committee. If you have concerns or complaints about the conduct of this study, please contact the Executive Officer of the HREC (Tasmania) Network on (03) 6226 7479 or email [human.ethics@utas.edu.au](mailto:human.ethics@utas.edu.au). The Executive Officer is the person nominated to receive complaints from research participants. Please quote ethics reference number H0014922.



#### **8. Do I have to take part in this study?**

It is important that you understand that your involvement in this study is entirely voluntary. While we would be pleased to have you participate, we respect your right to decline without having to explain the reason to us. There will be no consequences for you if you decline, and this will not affect your treatment or the care that you receive. You can stop being a part of this study at any time without giving a reason.

If you do wish to be involved, let (Karen Kennedy) know next time you see her in Longleaf and she will provide you with a Consent to Participate form.

**Thank you for taking time to consider this study. This information sheet is for you to keep.**



**SCHOOL OF ARCHITECTURE & DESIGN, and SCHOOL OF HEALTH SCIENCES,  
UNIVERSITY OF TASMANIA**

**PROJECT INFORMATION SHEET: RESIDENT**

**EXPLORING THE ARCHITECTURE OF WELL-BEING FOR AGEING-IN-PLACE**

The views of residents in care homes are very important to us. Thank you for taking time to read this Project Information Sheet.

**Invitation**

You are invited to participate in a PhD research study about the architecture of well-being for ageing-in-place, exploring how the design of aged care homes can enhance well-being through the support of caring relationships for residents, their families, and staff carers.

The study is being conducted by:

Karen Kennedy, Architect and PhD Candidate, School of Architecture & Design, and the School of Health Sciences, University of Tasmania

Dr Ceridwen Owen, School of Architecture & Design, University of Tasmania

Professor Andrew Robinson, Wicking Dementia Research and Education Centre, University of Tasmania

Emeritus Professor Roger Fay, School of Architecture & Design, University of Tasmania

**1. What is the purpose of this study?**

The aim of the study is to provide a comprehensive, in-depth understanding about the lived experiences of people living in a typical Australian aged care home, and their family and staff carers. This study explores how the design of aged care homes could be improved to support quality ageing in place, and the well-being of everybody in the care relationship.

**2. Why have I been invited to participate in this study?**

You have been invited to participate because you are a resident of Longleaf and you have first-hand experience of how the design of Longleaf affects your sense of well-being, your family's sense of well-being and how it supports or otherwise your relationships with your family and care staff.

**3. What does the study involve?**

The study involves the researcher working voluntarily Longleaf assisting with day-to-day care tasks to become immersed in the lives of people living and working in a typical Australian aged care home. This will help to build rapport and familiarity with residents, family, and care staff, and to provide the researcher with a sense of their lived experiences.

Over a period of several months, the researcher will be engaging in everyday conversations and observations of interactions between residents, and their families and care staff in the discuss concerns or questions about this study with them.

Aged Care Inc. home. The researcher will take photographs focussing on how the building design supports residents, family, and care staff relationships. The study includes one-to-one conversational

style interviews with residents, their families, and care staff to talk about the photos, their experiences of life in Longleaf how the design of the building enhances their well-being and supports their relationships.

In addition, the researcher will also be analysing the architectural brief and drawings and engaging in a conversation with both the architect and care manager of Longleaf about the focus and intentions of the design and the resulting building.

If you choose to participate, you will be involved a conversational style interview with the researcher of approximately 45 to 60-minute duration. During the research conversation, we will select your preferred photos and you will be asked whether you are happy for the photos to be used in research publications about the study or conference presentations. You do not have to consent for any photos to be used this way. You can still participate in the research conversation (s) even if you don't want photos to be used in publications or presentations.

The conversation will be about your personal experiences of how the environment does or does not support you and your relationships with your family and care staff. You will have an opportunity to talk about your thoughts on the design Longleaf, what you like about it and if you think it needs improving, and finally to make suggestions about how it could be improved.

Your relative (name) will be sitting in on the research conversations. They may simply listen in, or if appropriate help you to remember things or let the researcher know if they think it is time to stop the conversation or change the subject because you are getting tired, feel unwell or unhappy. You can also stop or postpone the conversation anytime you wish without explaining why. A month or so after the first conversation, you can choose to be involved in a second similar style research conversation to talk about the researcher's interpretations. You can add to or change anything from the first conversation if you wish. (Relatives name) will also be present at this research conversation too.

The research conversations will be audio recorded and typed up word-for-word to be used for analysis and interpretation by the researcher. The researcher is happy to provide you with a copy of the transcript of your research conversation at your request for you to check, and if you wish, you may amend.

Please be assured the research is in no way about assessing, making judgement, or reporting on the performance of discuss concerns or questions about this study with them.

Aged Care Inc., you or your family, or the quality of care received. The study will have no impact on your care and anything you say will be confidential and not reported to the staff or the organisation. Your identity and personal information will be treated with utmost respect and remain confidential. The conversational interviews will be held in your room, unless you prefer another place in Longleaf.

#### **4. Are there possible benefits from participation in this study?**

This is an opportunity to collaborate with the researcher/architect so that a more comprehensive understanding of the experiences of residents, families, and care staff in Australian aged care homes can be gained. The aim of the research is to improve the design of future aged care homes so that residents, family, and care staff relationships are supported, and their well-being enhanced.

It is unlikely that this study will lead to changes to the design of your present care home or your room, but you may be helping to make a positive difference to the lives of other people in aged care homes in the future. While the study is not intended to be therapeutic, you might find it beneficial to have a chance to tell your story to someone who is very interested in what you have to say.

Taking part in the study should be an interesting and rewarding experience and participants in similar studies have reported the experience as very positive.

The study has implications for developing strategies to improve future Australian aged care home design, policy, design guidelines, and funding. The outcomes are intended to educate future architects, and to provide comprehensive, qualitative information about the lived experiences of people within an Australian aged care home that are often not available otherwise.

#### **5. Are there any disadvantages or risks in taking part in the study?**

Sometimes talking about your personal experiences can trigger memories that can be upsetting. The researcher is very sensitive and will be careful in research conversations, but if you become upset, the researcher and your family will know to change the topic, or to postpone or cancel the research conversation. One of your nurses will also periodically monitor the conversation and will intercede if appropriate and make sure that you are well.

There is also a chance someone could recognise you or your relative from the photos. That is why we ask you to select and approve of photographs for use in publications and presentation.

#### **6. How will my information be kept private?**

All information will be treated with respect and confidentiality, and your name, your relative's name, the name of your care home and location, or any other identifying information will not be used in publications about the research. When we write the research report and any publications or give presentations, we may use some of the phrases you have said, but they will not be identifiable, as we will only ever use the pseudonym that you chose for yourself.

The research and focus group audio recordings and transcripts will be kept in a secure location on the University of Tasmania password protected server and on a password protected computer in the remotely located secured home of the researcher. All electronic data will be deleted 5 years after study findings have been published.

If you give permission to use photographs of you, or transcripts of your research conversations and afterwards change your mind, you can contact Karen Kennedy, and they will be removed from any papers or presentations. Please note that this cannot happen if the paper has been published or presentation already happened.

#### **7. What if I have questions about this study?**

Karen is happy to answer any questions or concerns and discuss the study in more detail at any time either in Longleaf or you can phone her mobile 04.....

The Chief Investigator Dr Ceridwen Owen (UTAS School of Architecture and Design, telephone. 03 6324 4479) or Professor Andrew Robinson (Wicking Dementia Research and Education Centre, UTAS, telephone. 03 6226 473) are overseeing this project to ensure it is a high-quality study. You may also discuss concerns or questions about this study with them.

Aged Care Inc. has kindly provided approval and supports this study.

This study has been approved by the Tasmanian Social Science Research Ethics Committee. If you have concerns or complaints about the conduct of this study, please contact the Executive Officer of the HREC (Tasmania) Network on (03) 6226 7479 or email [human.ethics@utas.edu.au](mailto:human.ethics@utas.edu.au). The Executive Officer is the person nominated to receive complaints from research participants. Please quote ethics reference number H0014922.

**8. Do I have to take part in this study?**

It is important that you understand that your involvement in this study is entirely voluntary. While we would be pleased to have you participate, we respect your right to decline without having to explain the reason to us. There will be no consequences for you if you decline, and this will not affect your treatment or the care that you receive. You can stop being a part of this study at any time without giving a reason.

If you do wish to be involved, let (Karen Kennedy) know next time you see her in Longleaf and she will provide you with a Consent to Participate form.

**Thank you for taking time to consider this study. This information sheet is for you to keep.**



**SIMPLIFIED CONSENT TO PARTICIPATE FORM: RESIDENT**  
**EXPLORING THE ARCHITECTURE OF WELL-BEING FOR AGEING-IN-PLACE**

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1. (Resident's relative's name) and Karen have talked to me about this study.  
☐ Usual form of assent/ consent noted by researcher, family or staff carer
2. They have explained what I will be asked to do.  
☐ Usual form of assent/ consent noted by researcher, family or staff carer
3. I understand that Karen will be spending some time in the care home where I live. She will be talking to me about my life in my care home. She will take photographs of me with my family and carers in my care home. She will talk to me about the photos.  
☐ Usual form of assent/ consent noted by researcher, family or staff carer
4. I understand that (family member's name) or (staff carer's name) will sit with me during these talks with Karen.  
☐ Usual form of assent/ consent noted by researcher, family or staff carer
5. I understand that if I become upset during the study, one of the registered nurses that take cares of me in my care home will comfort me.  
☐ Usual form of assent/ consent noted by researcher, family or staff carer
6. I understand that all information about me will be kept private and secure.  
☐ Usual form of assent/ consent noted by researcher, family or staff carer
7. Any questions that I have asked have been answered so that I understand what is being asked of me.  
☐ Usual form of assent/ consent noted by researcher, family or staff carer
8. I understand that Karen may use photographs and parts of our conversation when she writes or talks about this study. I understand that my name and address will be kept private.  
☐ Usual form of assent/ consent noted by researcher, family or staff carer
9. I agree to take part in this study.
10. I understand that I may stop being part of the study at any time and do not have to explain why. Karen will not include my photos or my conversations in the study.  
☐ Usual form of assent/ consent noted by researcher, family or staff carer

***To be signed and returned to investigators prior to research task:***

Resident's name:

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Family Member/ Welfare Guardian's Name:

---

Relationship to resident participant:

---

Signature:

Date:

---

**Statement by Researcher**

☐

I have explained the project & the implications of participation in it to this volunteer participant and I believe that the consent is maximally informed given their cognitive capacity and that he/she has sufficient understanding of the implications of participation

Name of Researcher:

Signature of Researcher:

---

***To be consented to at the beginning of each research conversation:***

***Research Conversation 1 dated.....***

I understand that Karen has come to talk to me now about my life in this care home and I agree that this is agreeable to me.

☐ Usual form of assent/ consent noted by researcher, family or staff carer

Name of Researcher:

Signature of Researcher:

***Research Conversation 2 dated.....***

I understand that Karen has come to talk to me now about my life in this care home and I agree that this is agreeable to me.

☐ Usual form of assent/ consent noted by researcher, family or staff carer

Name of Researcher:

Signature of Researcher:

***To be consented to prior to the first research conversation:***

**I consent to have photographs of me, and my conversations used in talks or writing about this study.**

☐ Usual form of assent/ consent noted by researcher, family or staff carer

Name of Researcher:

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Signature:

Date:

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**SIMPLIFIED CONSENT TO PARTICIPATE FORM: RESIDENT  
(VERBAL-RECORDED)**

**EXPLORING THE ARCHITECTURE OF WELL-BEING FOR AGEING-IN-PLACE**

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1. I have read the 'Project Information Sheet' together with one of my family members.
2. The study and what I will be asked to do have been explained to me.
3. I understand that Karen, the researcher, will be spending time in the care home where I live. She will be talking to me about my life in my care home. She will take photographs of me with my family and carers in my care home. She will talk to me about the photos.
4. I understand that the researcher, Karen, will ask me if I want to talk about her thoughts on our earlier conversations.
5. I understand that one of my family or staff carers will sit with me during these conversations with Karen. They will be helping and if I become upset during the conversations, they will ask Karen to change or stop the conversation.
6. I understand that if I become upset during the study, one of the registered nurses who take care of me in my care home will comfort me.



7. I understand that all information about me will be securely stored on the University of Tasmania server and that it will be destroyed 5 years after any publications about this study.
8. Any questions that I have asked have been answered to my satisfaction.
9. I understand that photographs of me, or parts of my recorded research conversations may be used in publications and presentations about this study, but that my name and my address will be kept private.
10. I agree to take part in this study.
11. I understand that I may stop being part of the study at any time and do not have to explain why. I understand that I may ask that photographs of me or anything that I have said to the researcher, is not included in the study unless it has already been used in a publication or presentation.

***To be signed and returned to investigators prior to research task:***

**General consent**

Resident's name:

---

Signature:

Date:

---

Family Member's/ Welfare Guardian's Name:

---

Relationship to resident participant:

---

Signature:

Date:

---

**Statement by Researcher**

☐

I have explained the project & the implications of participation in it to this volunteer participant and I believe that the consent is informed and that he/she understands the implications of participation

Name of Researcher:

Signature of Researcher:

***To be signed at research conversation:***

**I consent to have photographs of me selected together with Karen, the researcher, used in publications and/or presentations.**

Name of Participant:

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Signature:

Date:

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**I consent to have de-identified quotes from my conversation(s) with Karen in publications and conference presentations**

Name of Participant:

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Signature:

Date:

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**APPENDIX 4: Family- Invitation to participate, information sheet, and consent to participate forms including proxy consent to participate for residents**

Note: Staff forms were very similar and have not been included in the appendices.



**SCHOOL OF ARCHITECTURE & DESIGN, and SCHOOL OF HEALTH SCIENCES,  
UNIVERSITY OF TASMANIA**

**INVITATION TO PARTICIPATE GUIDE (VERBAL): FAMILY  
EXPLORING THE ARCHITECTURE OF WELL-BEING FOR AGEING-IN-PLACE**

You are invited to be part of a research project that is being undertaken by researchers at the University of Tasmania:

Dr Ceridwen Owen, Acting Head of School, Architecture & Design

Emeritus Prof Roger Fay, School of Architecture & Design

Prof Andrew Robinson, Co-Director, Wicking Dementia Research and Education Centre

Karen Kennedy, PhD Candidate, School of Architecture & Design

**This PhD research project is about the architecture of well-being for ageing-in-place.**

The aim of this study is to provide an in-depth exploration of how design of aged care homes enhances well-being by supporting caring relationship for residents, their family, and care staff.

This research explores how the design of nursing homes could better support quality ageing in place. It explores the ways in which the built environment can enhance well-being by supporting the care relationships of residents, their families, and care staff.

I, Karen Kennedy have been and will continue to work voluntarily for some months within Longleaf allowing time to experience the built environment, build rapport with residents, family and care staff, and to provide an opportunity for considerable observation time and research conversations allowing me to develop an in-depth understanding of life in an aged care home.

The study involves engaging in everyday conversations and observations of interactions between residents and their families, and care staff in the Aged Care Inc. home. I will take photographs focussing on how the aged care home design supports residents, family, and staff carers' relationships. If you choose to participate, you will be involved a one-to-one conversational style interview with me of approximately 45 to 60-minute duration.

The first part of the conversation will be about your relative in preparation for a future conversation with them. Together we will collaborate to design the ideal way to engage with your relative so that they can tell their story as best as they possibly can. You can tell me about their usual ways of communicating, signs of fatigue or distress, the subjects that might upset them, personal props that might help them to talk about their life in the care home, and anything else you think could help your relative to feel at ease.

The second part of the conversation will be more about you. We can discuss the photographs I took and your personal experiences of how the environment does or does not support you and your

relationships with your relative, and with other family members and care staff. You will have an opportunity to talk about your thoughts on the design of Longleaf, what you like about it, and if there is anything you think could be improved and finally to make suggestions about what you would do to make it a better place.

During the research conversation, you will be asked whether you are happy for the photographs that you have chosen for the conversation to be used in research papers that are published about the study or presented at conference presentations.

Ideally, you will also be present at the conversational style interview with your relative where you can choose to listen in, help them remember things or let me know if you think it is time to stop the conversation or to change the subject. Your relative can choose to be involved in a second similar style research conversation to talk about my interpretations and my research, or to add to or change anything from the previous conversation if they wish. Ideally, you will also be present at this research conversation too.

A few months after the conversations, there will be a family focus group and morning tea of approximately an hour to discuss my interpretations and my research, which you are welcome to attend if you wish. While we would be happy for you to participate in both the research conversation and the focus group, you can choose to participate in the research conversations but not the focus group if you wish.

The research conversations and focus group discussion will be audio recorded and transcribed for researcher analysis and interpretation.

Please be assured the research is in no way about assessing, making judgement, or reporting on the performance of Aged Care Inc., you or your family, or the quality of care received. The study will have no impact on the care of your relative and anything you say will be confidential and not reported to the staff or organisation. Your identity and personal information will be treated with utmost respect and remain confidential. The conversational interviews and focus group will be held in your relative's care home.

This study seeks a deeper understanding of the influence of the design of the aged care home on well-being from the perspective of residents, their family and care staff. It is unlikely that this study will lead to changes to the design of your relative's present care home, but you may be helping to make a positive difference to the lives of people in aged care homes in the future. It also gives you a chance to tell your story.

The study has implications for developing strategies to improve the design of aged care home design, policy, design guidelines, and funding. The outcomes are intended for to educate future architects, and to provide comprehensive, qualitative information about the lived experiences of people within an aged care home that are often not available otherwise.

If you are interested in being involved, have a think about it, discuss it with your relative (name), family, and friends, and please let me know the next time you see me in Longleaf and I will provide you with a Project Information Sheet and a Consent to Participate form. I am happy to answer any questions, discuss your concerns, and talk about the study in more detail at any time.

To be involved, I need both you and your relative (name) to agree to be a part of the study.

Once I have received your consent, I will contact you to arrange a time and place that best suits you for the conversational interview. I understand that there are a lot of demands on your time and I have designed this study to have minimal impact on you and your time with (relative's name).

If you have concerns about any aspect of this study, you can contact the Chief Investigator Dr Ceridwen Owen (UTAS School of Architecture and Design, telephone 03 6324 4479) or Professor Andrew Robinson (Wicking Dementia Research and Education Centre, UTAS, telephone. 03 6226 473) to discuss further.



**SCHOOL OF ARCHITECTURE & DESIGN, and SCHOOL OF HEALTH SCIENCES,  
UNIVERSITY OF TASMANIA**

**PROJECT INFORMATION SHEET: FAMILY**

**EXPLORING THE ARCHITECTURE OF WELL-BEING FOR AGEING-IN-PLACE**

The views of families are very important to us. Thank you for taking time to read this information sheet.

**Invitation**

You are invited to participate in a PhD research project about the architecture of well-being for ageing-in-place which explores how the design of aged care homes can enhance well-being by supporting the care relationships of residents, their families, and staff carers.

The study is being conducted by:

Karen Kennedy, Architect and PhD Candidate, School of Architecture & Design, and the School of Health Sciences, University of Tasmania

Dr Ceridwen Owen, School of Architecture & Design, University of Tasmania

Professor Andrew Robinson, Wicking Dementia Research and Education Centre, University of Tasmania

Emeritus Professor Roger Fay, School of Architecture & Design, University of Tasmania

**1. What is the purpose of this study?**

The aim of the study is to provide a comprehensive, in-depth understanding about the lived experiences of people living in a typical Australian aged care home, and their family and staff carers. This study explores how the design of aged care homes could be improved to support quality ageing in place, and the well-being of everybody in the care relationship.

**2. Why have I been invited to participate in this study?**

You have been invited to participate because you have a relative living in Longleaf and you have first-hand experience of how the design of Longleaf affects your sense of well-being, your relative's sense of well-being and how it supports or otherwise your relationship with your relative and their care staff.

**3. What does the study involve?**

The study involves the researcher working voluntarily in Longleaf assisting with day-to-day care tasks to become immersed in the lives of people living and working in a typical Australian aged care home. This will help to build rapport and familiarity with residents, family, and care staff, and to provide the researcher with a sense of their lived experiences.

Over a period of several months, the researcher will be engaging in everyday conversations and observations of interactions between residents and their families, and care staff in the Aged Care Inc. home. The researcher will take photographs focussing on how the building design supports

residents, family, and care staff relationships. The study includes one-to-one conversational style interviews with residents, their families, and care staff to talk about the photos and their experiences of life

The study involves the researcher working voluntarily in Longleaf, and how the design of the building enhances well-being. Following these conversations, there will be a staff focus group and a family focus group to talk about the researcher's findings and interpretations of those conversations.

In addition, the researcher will also be analysing the architectural brief and drawings and engaging in a conversation with both the architect and care manager of Longleaf about the focus and intentions of the design and the resulting building.

If you choose to participate, you will be involved a conversational style interview with the researcher of approximately 45 to 60 minute duration. The first part of the conversation will be about your relative to prepare for a future conversation with them. Together with the researcher, you will be asked to collaborate on the design of the ideal way to engage with your relative so that they can tell their story as best as they possibly can during their interview. You will be asked about their usual ways of communicating, signs of fatigue or distress, the subjects that might upset them, personal props that might help them to talk about their life in the care home, and anything else you think could help your relative. Together, we will select your preferred photos to use in the conversation with your relative.

The second part of the conversation will be about you. The researcher will discuss the photographs of you with your relative and your personal experiences of how the environment does or does not support you and your relationship with your relative and care staff. You will have an opportunity to talk about your thoughts on the design of Longleaf, what you like about it and if you think it needs improving and finally to make suggestions about how it could be improved.

During the research conversation, you will be asked whether you are happy for the photographs you have chosen to be used in research publications about the study or conference presentations. You do not have to consent to any photos being used in this way, or you can choose particular photographs that you are happy to be used. You can still participate in the research conversations and family focus group even if you do not want your photographs to be used in publications or presentations.

Ideally, you will also be present at the conversational style interview with your relative where you can choose to simply listen in, or to be involved and help them remember things and let the researcher know if you think it is time to stop the conversation or change the subject. Your relative can choose to be involved in a second similar style research conversation to talk about the researcher's interpretations, or to add to or change anything from the previous conversation if they wish. Ideally, you will also be present at this research conversation.

A few months after the conversations, there will be a family focus group discussion and morning tea of approximately an hour's duration to discuss the researcher's interpretations and findings. While we would be happy for you to be involved in the research conversations and the focus group, you can still participate in the research conversations even if you choose not to participate in the focus group.

The research conversations and focus group will be audio recorded and typed up word-for-word to be used for analysis and interpretation by the researcher. The researcher is happy to provide you with a copy of the transcript of your research conversation at your request for you to check, and if you wish, you may amend.



Please be assured that the research is in no way about assessing, making judgement, or reporting on the performance of Aged Care Inc., you or your family, or the quality of care received. The study will have no impact on the care of your relative and anything you say will be confidential and not reported to the staff or organisation. Your identity and personal information will be treated with utmost respect and remain confidential. The conversational interviews and focus group will be held in your relative's care home.

#### **5. Are there possible benefits from participation in this study?**

This is an opportunity to collaborate with the researcher/architect so that a more comprehensive understanding of the experiences of Australian aged care homes from the perspective of residents, families, and care staff. The aim of the research is to improve the design of future aged care homes so that residents, family, and staff carer relationships are supported, and their well-being enhanced.

It is unlikely that this study will lead to changes to the design of your relative's present care home, but you may be helping to make a positive difference to the lives of people in aged care homes in the future. While the study is not intended to be therapeutic, you might find it beneficial to have a chance to tell your story to someone very interested in what you have to say. Taking part in the study should be an interesting and rewarding experience and participants in similar studies have reported the experience as very positive.

The study has implications for developing strategies to improve future Australian aged care homes design, policy, design guidelines, and funding. The outcomes are intended to educate architects in the future, and to provide comprehensive, qualitative information about the lived experiences of people within an Australian aged care homes that are often not available otherwise.

#### **6. Are there any disadvantages or risks in taking part in the study?**

Sometimes talking about your personal experiences can trigger memories that may be upsetting. The researcher is very sensitive and will be careful in research conversations, but if either you or your relative become upset, the research conversation topic will be changed, or the conversation postponed, or cancelled. If you or your relative continue to feel upset, a registered nurse on Longleaf will be available to talk to you.

There is a chance someone could recognise you or your relative from the photographs. That is why we ask you to select and approve photos for use in publications and presentation.

#### **7. How will my information be kept private?**

All information will be treated with respect and confidentiality, and your name, your relative's name, the name of the care home and location, or any other identifying information will not be used in publications about the research. When we write the research report and publications, or give presentations, we may use some of the phrases you or your relative have said, but they will not be identifiable as we will only ever use the pseudonyms that you chose for yourself and for your relative.

The research and focus group audio recordings and transcripts will be kept in a secure location on the University of Tasmania password protected server and a password protected computer in the remotely located secured home of the researcher. All electronic data will be deleted 5 years after study findings have been published.

If you give permission to use photographs of you or your relative, or transcripts of your research conversations and afterwards change your mind, you can contact Karen Kennedy, and they will be

removed from any papers or presentations. Please note that this cannot happen if the paper has been published or the presentation has already been given.

#### **8. What if I have questions about this study?**

Karen is happy to answer any questions or concerns and discuss the study in more detail at any time either in Longleaf or you can phone her mobile 04.....

The Chief Investigator Dr Ceridwen Owen (UTAS School of Architecture and Design, telephone 03 6324 4479) or Professor Andrew Robinson (Wicking Dementia Research and Education Centre, UTAS, telephone 03 6226 473) are overseeing this project to ensure it is a high-quality study. You may also discuss concerns or questions about this study with them.

Aged Care Inc. has kindly provided approval and supports this study.

This study has been approved by the Tasmanian Social Science Research Ethics Committee. If you have concerns or complaints about the conduct of this study, please contact the Executive Officer of the HREC (Tasmania) Network on (03) 6226 7479 or email [human.ethics@utas.edu.au](mailto:human.ethics@utas.edu.au). The Executive Officer is the person nominated to receive complaints from research participants. Please quote ethics reference number H0014922.

#### **8. Do I have to take part or consent to my relative taking part?**

It is important that you understand that both your involvement and that of your relative living in the care home in this study is entirely voluntary. While we would be pleased to have you both participate, we respect your right to decline without explanation to us. There will be no consequences for you or your relative if you decline and this will not affect the treatment of you or the care your relative receives. You or your relative living in the care home can stop being a part of this study at any time without giving a reason.

If you do wish to be involved, I need both you and your relative (name) to agree to be a part of the study. Please let me (Karen Kennedy) know on the next time you see me on Longleaf and I will provide you with two Consent to Participate forms; one on behalf of your resident relative and one for you.

**Thank you for taking time to consider this study. This information sheet is for you to keep.**



## CONSENT TO PARTICIPATE FORM: PROXY FOR RESIDENT

### EXPLORING THE ARCHITECTURE OF WELL-BEING FOR AGEING-IN-PLACE

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1. I have read and understood the 'Project Information Sheet'.
2. The nature and possible effects of the study have been explained to me.
3. I understand this study involves the researcher engaging in everyday conversations with and observations of my relative as they interact with me and with their staff carers in the aged care home. The researcher will be taking photographs of my relative focussing on how the Australian aged care home design supports him or her, and his or her relationship with others.
4. I understand that I will be involved in a research conversation. The first part of the conversation will be to discuss my relative's usual ways of communication, signs of fatigue, or distress, assent or dissent, and personal props that might be useful to support my relative in his or her research conversation.
5. I understand my relative will be involved in a research conversation about their experiences of living in the care home environment. The researcher may use some of the photos that we selected together or personal props to help prompt my relative in the research conversation. If my relative chooses, I understand that he or she may be involved in a second research conversation to talk about, add to, or amend details of the first research conversation. I understand that another family member, a staff carer, or myself, will be present at both research conversations with my relative. I understand that the research conversations will be audio recorded.
6. I understand a registered nurse overseeing the care of my relative will be available to monitor him or her while the research conversations are occurring and to intercede should any signs of distress occur, and to provide emotional support.
7. I understand that research data will be securely stored on the University of Tasmania server and that this data will be destroyed 5 years after the publication of a paper about this research.
8. Any questions that I have asked have been answered to my satisfaction.
9. I understand that if I give consent, photographs of my relative and parts of the recording from his or her research conversations may be used in publications or presentations related to this research and this may mean that my relative or members of my family are identifiable. I understand that my relative can participate in the research conversation, but not give consent for photographs of her or him or parts of the recording to be used in publications or

presentations. I agree that any other research data gathered from my relative may be published provided that she or he cannot be identified as a participant.

10. I understand that the researchers will protect my relative's identity and that information he or she supplies to the researchers will be treated as confidential and will only be used for the purposes of the research. My relative's name will be protected by a participant-preferred pseudonym. The name and location of my family member's care home will be protected.
11. I agree that my relative may participate in this research. I understand that I may withdraw my consent for my relative to participate at any time without explanation, and if I so wish, may request that any data (including photographs of my relative or his or her research conversation transcript) be withdrawn from the research, unless it has already been used in a publication or presentation.

***To be signed and returned to investigators prior to research task:***

Resident's name:

---

Family Member's/ Welfare Guardian's Name:

---

Relationship to resident participant:

---

Signature:

Date:

---

**Statement by Researcher**

☐

I have explained the project and the implications of participation in it to this volunteer and I believe that the consent is informed and that he/she understands the implications of participation

Name of Researcher:

Signature of Researcher:

---

***To be signed at research conversation:***

**I consent to have photographs selected in collaboration with the researcher used in publications and / or presentations.**

Name of Participant:

---

Signature:

Date:

---

**I consent to have de-identified quotes from my relative's research conversations in publications and conference presentations**

Name of Participant:

---

Signature:

Date:

---



## **CONSENT TO PARTICIPATE FORM: FAMILY**

### **EXPLORING THE ARCHITECTURE OF WELL-BEING FOR AGEING-IN-PLACE**

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1. I have read and understood the 'Project Information Sheet'.
2. The nature and possible effects of the study have been explained to me.
3. I understand this study involves the researcher engaging in everyday conversations and observations of me as I interact with my relative and their staff carers in the Aged Care Inc. home. The researcher will be taking photographs of me focussing on how the design of the residential aged care facility supports me, and my relationship with others. I will then take part in a research conversation. The first part of the conversation will be to discuss my relative's usual ways of communication, signs of fatigue or distress, assent or dissent, and personal props that might be useful to support my relative in his or her research conversation. The second part of the conversation will be to discuss the photographs of me, and my experiences of the care home environment. If I choose, I may participate in a family focus group discussion and morning tea to discuss the researcher's interpretations. I understand that the research conversation and focus group will be audio recorded.
4. I understand that if I become upset during this part of the study, I am able to access support from one of the registered nurses overseeing the care of my relative at Aged Care Inc. in The Village.
5. I understand that research data will be securely stored on the University of Tasmania server and that this data will be destroyed 5 years after publications about this research.
6. Any questions that I have asked have been answered to my satisfaction.
7. I understand that if I give consent, photographs of me and/or parts of the recording from my research conversation and family focus group discussion may be used in publications or presentations related to this research. This may mean that me, or members of my family are identifiable. I understand that I can choose to participate in the research conversation and family focus group discussion, but not give consent for photographs of me and/or parts of the recording to be used in publications or presentations. I agree that any other research data gathered from me may be published provided that I cannot be identified as a participant.
8. I understand that the researchers will protect my identity and that information I supply to the researchers will be treated as confidential and will only be used for the purposes of the research. My name will be protected by a pseudonym that I have nominated for the researcher to use. The name and location of my family members care home will be protected.
9. I agree to participate in this research and understand that I may withdraw at any time without any explanation, and if so, I may request that any data (including photographs of me and my

research conversation transcript) may be withdrawn from the research, unless it has already been used in a publication or presentation.

***To be signed and returned to investigators prior to research task:***

**General consent**

Name of Participant:

Signature:

Date:

**Statement by Researcher**

☐

I have explained the project and the implications of participation in it to this volunteer and I believe that the consent is informed and that he/she understands the implications of participation

Name of Researcher:

Signature of Researcher:

***To be signed at research conversation:***

**I consent to have photographs selected in collaboration with the researcher used in publications and / or presentations.**

Name of Participant:

Signature:

Date:

**I consent to have audio and/or quotes from my research conversation and family focus group used in publications and conference presentations**

Name of Participant:

Signature:

Date:

## **APPENDIX 5: Resident, family, and staff- Prompted conversation guides**



**SCHOOL OF ARCHITECTURE & DESIGN AND SCHOOL OF HEALTH SCIENCES,  
UNIVERSITY OF TASMANIA**

**PROMPTED CONVERSATION GUIDE: RESIDENT**

**EXPLORING THE ARCHITECTURE OF WELL-BEING FOR AGEING-IN-PLACE**

**Check with resident's family and carer that proceeding with scheduled resident prompted conversation is appropriate today and that no other care tasks or health appointments are scheduled, and that resident is perceived to be in relative good health.**

**Communication Strategies**

- Have small notebook and recording device so as not to distract the resident. Have them prepared prior to the conversation to minimise fussing in the resident's room.
- Dress in clothes that are of warm colours, comfortable, and with simple patterns that are not overly fussy or distracting. The intention is to be as normal as possible and not to appear as a researcher or person of authority.
- Unless otherwise preferred by the resident, the prompted conversation will be held in their room to provide a comfortable, familiar space and to use the environment as a cue for the conversation.
- Check the environment is comfortable to help the resident relax and achieve the best outcome. Minimise noises and interruptions. Ensure appropriate lighting and temperature.
- Allow plenty of time so the prompted conversation is held at a relaxed pace and not time limited or outcome based. Let the resident guide the pace.
- Approach the resident from the front.
- Sit comfortably and with eye level at the same as that of the resident.
- Show interest and respect by maintaining eye contact and relaxed body language.
- Be calm, patient and don't interrupt. Be focused on the present.
- Read facial expressions and gestures, for they are likely to reveal more than the person's words. Gestures may sometimes replace forgotten words.
- Enter their world with them. Remember that whatever they are expressing is where they are at that point in time.



- Offer comfort and reassurance especially when the person is having difficulty expressing themselves. Offer praise for any accomplishments (e.g., completing a thought, reciprocating in an activity).
- Avoid criticism, correcting and arguing, as this can be traumatic to the person.
- Reminiscence and personal story telling is a key ingredient for success.
- Focus on feelings, not facts, and encourage non-verbal communication. Do NOT ask questions that require recall, accurate memories, or factual correctness. Do NOT correct factual inaccuracies.
- Speak to the resident as an adult and don't be condescending. Do not use 'elderspeak.'
- Use short, simple, familiar words and sentences.
- Focus on simple questions and one idea at a time.
- Questions may need to be rephrased if at times if the resident is unable to respond.
- Minimise the questions and let the resident speak freely. Listen and affirm by nodding in agreement and paying attention. Ask open-ended questions.
- If the resident wanders far from the topic, allow for a reasonable amount of time and then gently return the conversation by using a prompt such as the room, photo, or personal prop.
- Take on a similar posture to theirs to develop rapport and to be on their level.
- To minimise questions of residents, the researcher will have recorded basic information- age, previous occupation, and education, length of time living in Longleaf during prompted conversations with family and staff carers.
- The researcher will also have developed a personal biography for each resident during prompted conversations with family carers identifying usual forms of communication, signs of fatigue or stress, and will have selected suitable biographical conversation props and/or photographs.
- Prompts used in the conversation may include photos of residents interacting with other residents, families, or staff carers or personal props selected by family.
- Conversation prompts will include the aged care built environment, furnishings, and soft furnishings.
- The prompted conversation will be as close to a normal, equally partnered conversation as practical, starting with a warm up, then checking ongoing consent and then the 'research' prompted conversation. It is important to end informally and to ensure a careful withdrawal of the researcher. In the case of cognitively impaired residents, the resident is 'handed-over' to a family or staff carer.

- In a reciprocal manner, the researcher will share a personal story or experience. It might be about another activity in the care home today or what was for lunch.
- The intention of the conversation is that the resident and researcher are conversation partners. The approach is collaborative with real-time feedback, reflection, and affirming of shared contribution.

**Re-introduce the researcher and briefly describe the project and outline the process for today.  
Check ongoing consent.**

Hello (name of resident), I am Karen, and I am here today because I am doing a study on your care home and your family and care staff. This study explores how the design of care homes supports ageing-in-place and the well-being of everybody in the care relationship including you, your family, and the care staff. We talked earlier about your involvement in a research conversation about your experiences of living in Longleaf and about this room. We can take as long as you need but I expect this will take about an hour. (Name resident's relative or care staff) is here too.

Would you still like to be involved?

Are you feeling OK today? If not, would you like me to come back another time?

- ☐ Usual form of assent/ consent noted by researcher, family or staff carer
- ☐ Verified by family or staff carer. Signature.....

**Warm Up**

Are you comfortable? Are you warm enough? Would you like a cup of tea?

Talk generally about incidental topics that are familiar to the resident. The researcher will have some familiarity learned through volunteering. It may be the weather, what was for breakfast, or a piece of jewellery the resident is wearing.

**Prompted Conversation**

**Note:** not all questions are likely to be necessary. Allow your conversation partner to talk freely as many of the questions are likely to be answered without having to ask all questions.

I am going to record this conversation (show device).

Can you tell me about living in Longleaf?

Can you tell me about your room? How does your room make you feel?

Did you bring some of your things from your previous home with you? Can you tell me about those? Point to and talk about curtains? Ornaments? Own furniture or soft furnishings if applicable? The view through the window?

Looking at this photo, can you tell me a story about it (of resident and family or care staff)? Or name of specific personal prop? How does this photo/name of prop make you feel?

What do you like about your room? Is there anything you don't like about your room? The researcher may use environmental cues to prompt this question e.g. ask about lighting, view of or access to garden, noise etc.)

Did you or your family do anything to make your room more comfortable for you? (Researcher to point to items if necessary to prompt)

What is it like when your family (name) visits?

What is it like when your carer (name(s)) comes into your room?

Can you tell me about other rooms in care home (if applicable\*)? Lounge/ Dining/ Activity/ garden

\* If resident bedridden, this question will not be asked.

### **Additional/ Questions for Cognisant Residents**

Do you feel comfortable and at home here?

What has the experience of living in this room/ Longleaf and surrounding spaces meant for you?

What has it meant for your family?

(Using preselected photographs of social interactions taken by researcher prior to the conversation).

Looking at the photo (s), what can you tell me about how you were feeling in the photo? What does it look like the family/ staff carer was feeling in the photo?

What do you like about your room? Is there anything that you don't like about your room?

Is there anything that you would change? If you were to design this room/ Longleaf, what would you do differently?

How do you think this room/ Longleaf and surrounding spaces could be better so that your family feels more comfortable here?

How do you think this room/ Longleaf and surrounding spaces could be better so that your staff carer (s) feels more comfortable here?

### **Conclusion**

When I write about our conversation, what name would you like me to use instead of your real name? Or are you happy for me to call you (name selected by family) when I write about our conversation today.

Are you still happy for me to use the selected photos in publications or presentations?

Before I go, is there anything else you would like to tell me about your life here/your room?

### **Cool-down/ withdrawal**

Thank you for spending some time with me today. You have helped me understand more about what life is like for people living and visiting Longleaf. I think this information will help us to design better nursing homes for other people. Thanks for your help. (Turn recorder off)

Here is small thank-you gift (jam, biscuits or flowers as selected and approved by family or staff).

Your (family/ staff carer name) is here now to.....I'll be in again (name time/ day) to help out on the Longleaf. Bye for now and enjoy the rest of your day.



**SCHOOL OF ARCHITECTURE & DESIGN AND SCHOOL OF HEALTH SCIENCES,  
UNIVERSITY OF TASMANIA**

**PROMPTED CONVERSATION GUIDE: FAMILY**

**EXPLORING THE ARCHITECTURE OF WELL-BEING FOR AGEING-IN-PLACE**

Check with the family participant that the prompted conversation is still appropriate for today.  
Assure that rescheduling is OK.

- Minimise the questions and let the family member speak freely. Listen and affirm by nodding in agreement and paying attention. Ask open-ended questions.
- The prompted conversation will ideally be as close to a normal, equally partnered conversation as practical, starting with a warm up, then checking ongoing consent and then the 'research' prompted conversation.
- Prompts used in the conversation may include photos of families interacting with other family members, residents or other staff carers. Conversation prompts will include the aged care built environment, furnishings, and soft furnishings.
- In the researcher's experience as an architect talking to people about the design of buildings, people often appeared to find 'why' questions difficult to answer. 'How' questions were often easier and if asked well, the answers often lead to talking about why, about lived experiences and feelings. The researcher will use a similar approach in the prompted research conversations. The researcher will be identifying as an 'architect' who is researching how to improve the design of aged care homes, engaging the conversation partner/family carer in the spirit of collaboration and providing their professional and personal experience to give insight and help others.
- The intention of the conversation is that the family carer and researcher are conversation partners. The approach is collaborative, with real-time feedback, reflection, and affirming of shared contribution.

**Re-introduce the researcher, briefly describe the project, and outline the process for today. Check ongoing consent.**

Hello (name) today I am here as a researcher, and as you know, I am also an architect. This study explores how the design of aged care homes supports ageing-in-place and the well-being of everybody in the care relationship including you, your relative living in the care home, other relatives, and the care staff.

The first part of the conversation will be about your relative to prepare for a future conversation with them. We will talk about their usual ways of communicating, signs of fatigue or distress, the subjects that might upset them, personal props that might help them to talk about their life in the care home, and anything else that you think could help. We will also select photos to use in the conversation with your relative and your preferred photos to use in the study.

The second part of the conversation will be about you. We will start with a few basic details about you, then talk about your personal experiences of visiting Longleaf to spend time with your relative and how you feel about the design of the building and whether it supports your relationship with your relative, other family members, and care staff.

How long has (name resident) lived in Longleaf? \*

What is your relationship with (name resident)? Spouse/ adult child/ other\*

Age (within a 5-year bracket e.g. 40-45)

When do you normally visit?

**Note:** not all questions are likely to be necessary. Allow the conversation partner to talk freely as many of the questions are likely to be answered without asking all questions.

\*May not be required as researcher may have this information from working in Longleaf prior to prompted conversations.

### **Prompted Conversation - Part 1**

Can you tell me about the way (name resident) usually communicates? This may be verbal, sounds or non-verbal signs such as gestures and body language.

How does (name relative) normally agree or disagree to a request or a question?

What are typical signs that (name relative) is tiring, unhappy, distressed or unwell?

Are there any personal props that you think might help (name relative) to talk about their experiences here?

(Using preselected photographs of social interactions taken by researcher prior to the conversation).  
Looking at the photos, which of them do you think might help (name relative) to talk about their experiences and their relationships?

Can you suggest a pseudonym for your relative for use in publications or presentations about this research?

### **Prompted Conversation - Part 2**

Can you tell me about visiting here Longleaf? How does the design of the building make you feel?

How do you feel supported by the design of the building?

How do you feel that caring for (name resident) is supported by the design of the building?

How does the building support or not support you? Can you give examples?

Does the design of the building support your relationships with your relative? Others in your family? Care staff?

(Using preselected photographs of social interactions taken by researcher prior to the conversation). Looking at this photo, can you tell me about it (of resident and family or staff) and your relationship with the person/ people in it? Is the building design helpful in this situation?

Thinking about/ looking at some of the spaces/ rooms in Longleaf, what are your thoughts about them? How do they make you feel?

(If visually apparent to researcher) Did you or your family personalise (relative's name) room?

How do you think a care home should feel? How does it feel?

What do you like about the room/ Longleaf? Is there anything you don't like?

How could the building and surroundings be improved so that you and other family members feel more welcome? Would you visit more often? Would you like to visit more often? What might help you to spend more time here?

Has (name relative) been in this room since they came to live here? Do you expect they will be able to stay in this room? Would anything need to change to help your family member stay in their current room?

If you had a chance to redesign Longleaf, what would it look or feel like? What would you do differently?

How do you think Longleaf could be improved so that families and care staff feel more comfortable here?

## **Conclusion**

What name would you like me to use instead of your real name in publications or presentations about this research?

Are you still happy to use the selected photos in publications or presentations?

Remind the participant about the future family focus group. Remind them that the option to participate in further research is voluntary.

Before we finish, is there anything else you would like to tell me?

Thank you for spending some time with me today. You have been very helpful, and your contribution is valued and appreciated.



**SCHOOL OF ARCHITECTURE & DESIGN AND SCHOOL OF HEALTH SCIENCES,  
UNIVERSITY OF TASMANIA**

**PROMPTED CONVERSATION GUIDE: STAFF  
EXPLORING THE ARCHITECTURE OF WELL-BEING FOR DEMENTIA AND AGEING-IN-PLACE**

Check prompted conversation is still appropriate today – Longleaf is not short-staffed or other care needs of residents a priority. Assure that rescheduling is OK.

- Minimise the questions and let the staff carer speak freely. Listen and affirm by nodding in agreement and paying attention. Ask open-ended questions.
- The prompted conversation will ideally be as close to a normal, equally partnered conversation as practical, starting with a warm up, then checking ongoing consent and then the 'research' prompted conversation.
- Prompts used in the conversation may include photos of staff interacting with families, residents or other staff carers. Conversation prompts will include the aged care built environment, furnishings, and soft furnishings.
- In the researcher's experience as an architect talking to people about the design of buildings, people often appeared to find 'why' questions difficult to answer. 'How' questions were often easier and if asked well, the answers often lead to talking about why, and about lived experiences and feelings. The researcher will use a similar approach in the prompted research conversations. The researcher will be identifying as an 'architect' who is researching how to improve the design of aged care homes, engaging the conversation partner/family carer in the spirit of collaboration and providing their professional and personal experience to give insight and help others.
- The intention of the conversation is that the staff carer and researcher are conversation partners. The approach is collaborative, with real-time feedback, reflection, and affirming of shared contribution.

**Re-introduce the researcher, briefly describe the project, and outline the process for today. Check ongoing consent.**

Hello (name) today I am here as a researcher, and as you know, I am also an architect. This study explores how the design of care homes supports ageing-in-place and the well-being of everybody in the care relationship, you, the residents in your care, including those with dementia, their family members, and other care staff.

We will start with a few basic details about you, then talk about your personal experiences of working here Longleaf and how you feel about the design of the building and whether it supports your relationship with the residents, their families, and other care staff.

How long have you worked here?

How long have you worked in aged care?

What is your position/ professional experience? \*

Are you employed full-time/ part-time or casually? \*

Which shifts do you most often work - weekdays, evenings, or weekends? \*

**Note:** not all questions are likely to be necessary. Allow conversation partner to talk freely as many of the questions are likely to be answered without asking all questions.

\*May not be required as researcher may have this information from working in Longleaf prior to prompted conversations.

### **Prompted Conversation**

Can you tell me about working here Longleaf? How does the design of the building make you feel?

Do you feel supported by the design of the building?

Is your work supported by the design of the building?

How does the building support or not support you or your work? Can you give examples?

It is interesting that Longleaf is both a place where people live and at the same time, your place of work. Do you think that is recognised by the designers and/or management?

How does the design of the building support your relationships with residents? Their families? Other care staff?

(Using preselected photographs of social interactions taken by researcher prior to the conversation). Looking at this photo, can you tell me about it (of resident and family) and your relationship with the person/people in it? Is the building design helpful in this situation?

Thinking about/looking at some of the spaces/rooms in Longleaf, what are your thoughts about them? How do they make you or others feel?

How do you think a care home should feel? How does it feel? How do you feel?

What do you like about Longleaf? Is there anything you don't like?

If you had a chance to redesign this Longleaf, what would it look or feel like? What would you do differently?



How do you think Longleaf could be improved so that families and care staff feel more comfortable here?

### **Conclusion**

What name would you like me to use instead of your real name in publications or presentations about this research?

Are you still happy to use the selected photos in publications or presentations?

Remind the participant about the future staff focus group discussion. Remind them that the option to participate in further research is voluntary.

Before we finish, is there anything else you would like to tell me?

Thank you for spending some time with me today. You have helped me understand more about what life is like for people living and visiting Longleaf.

**APPENDIX 6: Extracts from prompted conversations with a resident, a family member, and a staff member**

Tom spoke before the recorder was turned on about not being around for much longer. **Tom:** *'I am not going to be here much longer. One day I'll just lie in this bed and go. Well, I can't do much. I can't walk'.* **R:** *'Bernie will miss you'.* **Tom:** *'We have had a good life and it might be easier on her'.* *(Talked about life as a master mariner.) First, was Sydney, then Halifax, Nova Scotia, the Newport. I think I am going still now'.* **R:** *'It was an exciting life'.* **Tom:** *'It was.....'.*

**R:** *'Are you hurting right now? Do you need me to call a nurse'?* **Tom:** *'I'll get something later on. I'm all right...'* **R:** *'You seem a bit uncomfortable, do you need something'?* **Tom:** *'No, I am always uncomfortable. I am fine but I haven't had a shave. I went to the toilet, but it's really quite a business. They have to lift me up and wheel me around. Wheel me in and wheel me out, up onto the toilet and out again. It normally takes half an hour, three quarters of an hour'.*

**R:** *'That does seem a bit awkward. Could the room be a bit bigger'?* **Tom:** *'Well, I don't really utilise it. Bernie does. It could be better for her. Her house is I think, very nice for her. I won't be going back....'*

**R:** *'What makes a house nice'?* **Tom:** *'Having it the way you like it and keeping it nice. But I fell over there, and now, well it wouldn't surprise me if I never leave this hospital. I don't why I couldn't be with Bernie, I don't think I am asking for too much'.*

.....R: 'You've done some things here in her room, how did you go about that? Like the pictures here'. Kate: 'That was something I did quickly one morning to try and bring some reality into her. Um, telephone, little table and all her clothes, just help her recognise... The little bow on the door, the same as the rug'. R: 'I was wondering about the bow.' Kate: 'Yes, that was, that was it'. R: 'I noticed the rug. Did it come from home?' Kate: 'That's right. She used to sit and watch telly, put it over her legs. There is your rug. I brought it in. For familiarity...'

R: 'And I notice there is often lovely fresh flowers'. Kate: 'Well of course, they come from mum's garden'.

R: 'You have done a great job of making your mum's room comfortable for her. Did anyone help or support you to make your mum's room nice?' Kate: 'That would be the one thing that I would say I feel quite strongly about. I think we should... But there was a leaflet that said you can't put anything on the walls without asking. I was lucky that that picture frame hook was there, so I could find a picture frame that took one hook. As for anything else, we are not allowed to touch the walls according to this literature'.

R: 'If you could touch the walls, what would you do differently?' Kate: 'I would probably bring in...mum used to do beautiful tapestries; you know their house is full of these goddamn tapestries. But yeah, um.... Something, maybe that she's got in her bedroom or something that meant something to her. If I was allowed to put some more of her things around. You could put a nice bunch of flowers there and you know, a couple of pictures or something like that'. R: 'The room might need to be a little bit bigger'. Kate: 'That's right...'

Kate: 'The staff don't have any time for engagement. Don't get me wrong, the staff are lovely, and they smile, and they listen. I can see that all they are trying to do is get on to the next person. They are certainly not listening to the residents.

You ask what more could be done. I would like to see an outside area. That to me would be the most wonderful thing. To take mum out and sit on a bit of grass, with a coffee table with some trees around and take a cup of coffee is something that she has been able to do all her life. A little courtyard even, some grass, trees, plants'.

R: 'Ok, so you've just won the lotto. Don't think about what is here in Longleaf now, what would you design differently? Not re-working of what is here now but all new'. Kate: 'My idea is to make a home where it is designed for this full-time staff and they could all have their own little piece of paradise.

So in redesigning, allowing people to live together. That's my dream and that's probably only because I'm going through that with my parents. Dad is so lonely, and my dada has never, ever said he was lonely. To be so lonely after 76 years, be it good or bad 76 years (laughs). But after 76 years of having a wife to go home to, in one night their whole lives changed. My biggest issue is dad at 95, and mum here and them not being able to be together'.

R: 'How long have you work in Longleaf'? Jan: 'I worked with Aged care Inc. since 1990. So I worked at the old nursing home, the original one then I moved here when it was built. I have been with the dementia residents since I started in 1990'.

...R: 'Does that mean that you think we should be designing all care homes for dementia'? Jan: 'Yes, with the prevalence now, we need all aged care designed so that they are for the dementias'.

R: 'So, do you think that Longleaf should have been designed with dementia needs more in mind'?

Jan: 'Yes, for sure. There is not a lot you can do about it though. Once a building is built, it's built. I think they need to Mind you, I don't know what they were thinking when it was designed...Longleaf was built so that some have shared bathrooms and there is nowhere for them to wander. Up and down corridors, that's all they've got to wander which is not good for them'.

R: 'My interest is in both because I don't know that you can separate care, from building from people'. Jan: 'Absolutely, yes'. R: 'Can you do good care in a bad building or vice versa'? Jan: 'I would say yes to both. We had a really good cohesive team over there that came with me. The building over there was very old. It was built in 1939. It was the original nursing home and we had those 4-bed wards. And they had this thing where you sat in the middle. It was oval shaped, and it was so badly designed, but it was 1939, but the ambience there, the compliments we got from the residents' families. You walked in there and it was like "I'm home" and a lot of them said that to us. It was lovely. It was like one big family. All the families joined in, all the residents joined in. All the staff were fantastic. We had very little turn-over in staff. Once they came, they stayed. Everyone just loved going to work'.

Jan: 'But you talk to anyone that's worked there. They'll all say the same thing. It was old. It was grotty. I say grotty... but it was old fashioned, that's what it was. The bathrooms had 4 toilets and showers, and things like that, but the atmosphere was wonderful. We'll never recreate that. It wasn't recreated that in Longleaf.

But I think a lot of it's gone, and I don't think we will ever get that back, but I do think that small, intimate atmosphere.....old it was but more community feeling'.

R: 'So do you think moving up here made your work harder'? Jan: 'Oh, yes. I didn't feel, I have never felt...but you will never replicate the old nursing home. Never. It is very hard for the dementias in Longleaf because there is nowhere for them to just be, you know'.

Jan: 'This is a quote I was told. I don't know if it's true, but it's what I was told. It was designed by somebody who designs hotels, because they didn't want it to look like a nursing home and I think it's why we've got that bar thing for the nurses' desk and we've got all those things at the back, but no-one can see them. That's what I was told. Whether it is true, I don't know. And I don't think...um, we weren't asked. We weren't asked, at all.

It's not being an Einstein. It's not doing dementia courses. It's working with the people and thinking about things a bit'.

R: 'So how would an architect know this? What do architects need to know about people coming in older, more dependant...some of those in Longleaf now; they might live only a few months.... I don't know'. Jan: 'Two weeks even'. R: 'Do you think anyone thought about residents dying when they designed Longleaf'? Jan: 'Probably not, because (whispers) if somebody does die, you have to, you have to, if somebody dies this side, you have to go all the way around and down and through the main entrance. And if they die on that side of Longleaf, then there is no way you can get them out

the door without everybody in the dining room going [looking]. We have no screens. What we would do is hope that nobody wanders out into the dining room'. R: 'Do you think the residents know anyway'? Jan: 'They're not stupid. If you see a trolley covered with a body on it, well, it's obviously a body'.

R: 'So in Longleaf, particularly what are your thoughts about the dining room? Jan: Awful! It's too big. I mean, it's a dining room come sitting room. It's too big. It's very clinical. It's much too big. It's like a school dining room. Two rows all lined up. Plonk them in front of the television, all in rows'.

R: 'And what would you do differently'? Jan: 'I would have it smaller. I would have it, kind of, areas where you can come a just sit down. I think it's important to have an area where, a biggish area where people from all the wings can go and see a concert or something, but not make that the reason for having the big area. I think you need one area like that somewhere in a nursing home to bring them all together because they quite enjoy that. The ones that are more cognitively with it quite enjoy meeting people from other wings, but I don't think that should be the main purpose of Longleaf when they've got 40 people living there as their home. You need areas which are like a small lounge room that you would have at home where they can wander in and sit in a chair and not be surrounded by 39 other people'.

R: 'And what must it be like for families'? Jan: 'Awful. It's like sitting in an auditorium really, with your nearest and dearest, and then they get embarrassed because something happens, like someone farts in the middle of the dining room, and well, we don't care but to them that's awful. Or they'll swear or something and they'll apologise for their resident. Dementias call out, comes up and takes your cup of tea, and tips it on the floor'.

R: 'Do you think the building makes the families feel welcome'? Jan: 'No, not particularly. I think they could have done a lot more and given families a little kitchen. They could have made that a lot more homey and where they could go and sit to have a chat. It isn't good enough.

I don't know that we look after the families that well. Um I think there is a lot more we can do. I think there should be a quiet room where they can go, and make a cup of coffee..... I just don't think, you know, if you've got a big family, there's not a lot of room in the rooms for them...'

R: 'So, how do you think a care home should feel'? Jan: 'I think it should feel like the old nursing home, when we walked in, "I'm home". Honestly, that's how we all felt'. R: So what made it home?

Jan: 'It was just ambience. It was something when you walked in. It was just felt so good. And I don't know. Whether it was the staff, whether it was the atmosphere, we just. You didn't feel as though you were walking into a hospital. You didn't feel as though you were walking into a nursing home. You felt were walking into a place where we all lived together. It was really good. You ask anybody how they felt. A lot people still come up to me and say it was so good in the old nursing home. It had a lovely garden. It was a really old-fashioned thing. We had what was called the old Florence Nightingale ward and then outside of that, the whole of the side opened up and we had a big balcony and we had gardens and the view was magnificent. But the ambience was...I just can't tell you what it was'. R: 'So was there more of those meaningful moments'? Jan: 'Oh, definitely'. R: 'Because the opportunity was there'? Jan: 'It was small. Only 27 residents. And it was little bit higgledy-piggledy. Well, it was old. By today's standards, it was shocking. There was just something about it. I can't actually put it into words. You would need to have gone there...to feel it. We never lost staff. Everybody just stayed there. It was just so nice over there. It was lovely and they've never recreated over here, and they won't. Never! It is completely different, but that was built in '39'.

R: 'So if you were to redesign Longleaf, forget about budget and what is already there. You have a clean slate. What would you do'? Jan: 'It's too big to start with. You can't have 40 people in a unit

*for people with dementia. I don't know what I would do. I would make it smaller. I would make it more personal, more like a home. That [dining room] doesn't feel like home. It's more like a cheap hotel cafeteria. I would have kind of like a room for the relatives.*

*But as I said, Longleaf is nothing like the old nursing home. The staff and the family were all together. It was like one big family. It was beautiful. It was great. It had a nice atmosphere, very different from here [Longleaf]. There is too much stimulation here, not good stimulation either. The dementias just can't cope with it'.*

## **APPENDIX 7: Extract from a follow-up conversation with a resident**



### Excerpt from follow-up conversation with Joe

**Joe:** 'I don't like it here. My house in XXXX Crescent, I felt freedom. I could see who I wanted, we could watch the boats, we could sit and do what we wanted, or we could go out. I liked our street. Number XX is in a good area. We lived in a good area'.

**R:** '.....Do your belongings help make this feel like your special room'? **Joe:** 'No, I don't like it here'.

**R:** 'You don't like it here'? **Joe:** 'I like to be at XXXX Crescent. It is good quality'.

**R:** 'Why did you like XXXX Crescent'? **Joe:** 'Everything here is too cold. I don't like it'. **R:** 'Are there things that you miss'. **Joe:** 'Ja. Yes, the freedom, the freedom, and contact with people. Now, I am here all by myself. Liz, my wife, she ...might not come today'.

**R:** 'You were a pilot. You like freedom'. **Joe:** 'Yes, I used to fly, and go on my motorbike and in my car'. **R:** 'Is it movement or speed that you like'? **Joe:** 'I don't irresponsible speed. I am responsible. I have a very strong sense of self-preservation, but I don't like life as it is. My wife, she is staying in our house in XXXX Cres. It is a good area. We got a very nice house. We can see the shipping movement. We can see the passenger liners as they go overseas and when they come back'.

**R:** 'So now, you are staying here for a while'. **Joe:** 'Yes, I am staying here but I am trying to get back to XXXX Crescent, to number XX. Number XX XXXX Crescent, but I don't like it here. To be here more than another year at least, maybe 2 years. I don't like it. My wife is very popular with the people. She remembers their names. She is very clever'.

**R:** 'So does this place feel familiar to you'? **Joe:** 'No not my place at all. At XXXX Crescent, we had garden that was all herbs and climbers. Yes, at XXXX Crescent we had a huge... a huge garden deck. I love it there. I love it. The view and I mean, the quality, the quality. It was brick, solid'.

**R:** 'Are you talking about the quality of the building and of the materials'? **Joe:** 'Everything and my wife likes it too. She likes to have everything nicely too. She is very clever. She is more clever than I feel that I am. She's pretty good'.

**R:** 'So at XXXX Crescent, you had freedom and you liked that'. **Joe:** 'Yes, we had waiters at the hotel [Joe's childhood home], we had staff, and we had a piccolo. We bought XXXX Crescent together, my wife and I'. **R:** 'That sounds nice. And you liked it there'? **Joe:** 'Ja, ja. It was bricks, fairly small kind of brick, very dark. I don't like this here, this chair, all vinyl. I would never have vinyl'. **R:** 'What would you choose'? **Joe:** 'Leather or plush, plush....' **R:** 'Velvet'? **Joe:** 'Yes, velvet. Quality'. **R:** 'So this is not like you are used to, what you would have at home'? **Joe:** 'Nothing like my home'.

**Joe:** 'I could be happy too if my wife was here with me in this building'.

**APPENDIX 8- Extracts family and staff discussion groups- 10 and 12 March 2016**

## Discussion Group 1, 10 March 2016

Present: 3 CSEs, Jack, Warren, and Ben and one family member, Maree's husband, Angus.

## Discussion Group 2, 12 March 2016

Present: Joe's wife, Liz, Greg's wife, Paula, CSE: Connie, and RN: Meg

**R:** 'Home seemed to be expressed as a feeling, a concept or sense of a being-in-place, not simply a physical residential building. There were frequent expressions throughout the conversations that could be interpreted as *'not being-in-place'*. Residents used expressions like *'feeling lost'* or *'directionless'*. **Jack:** *'Yeah, some say they feel useless'*.

Some think they are in a club, in a hospital or a guesthouse. **Jack:** *'All the time. They don't know where they are. Some residents feel the need to ask every night if there is room in the guesthouse or hospital tonight or where are they going to sleep tonight'*.

.... **R:** 'I expected the research focus to be on the residents own room but found two groups of residents: the bedroom residents and the dining room residents'. **Ben:** *'Oh yeah, it is kinda like that'*. 'Residents are in the dining room where everything and yet nothing happens, or in their own room where sometimes there is very little activity'. **Ben:** *'yeah'*. 'In bedrooms, there is less likelihood of contact with other people, but in the dining room surrounded by strangers with perhaps a slightly increased chance to engage'. Ben: *'yes'*, 'but with more environmental stimulation than most can cope with, *(nodding in agreement by staff)*, inhibiting engagement, yet can still feel lonely'.

**Liz:** *'So talking about the dining room, I think it's barely OK. Some people just sit in their wheelchairs, not normal chairs so maybe it needs to be spacious, but it could be nice and cosy, say on the sides'*. **R:** *'I think that is what people were talking about when they said it was too big'*. **Paula:** *'There should be an area where the family, if they don't want to sit at the table; that you can sit at the side and still be a part of everything'*.

**Ben and Jack:** *'Yes, but there can be sort of too much going on'*.

.... **R:** The residents sometimes did not seem to know what their place was. There are things like this room for example, where often the doors are shut. **Liz:** *'Well, that's right because when I come down, staff are sitting here, and the doors are shut'*. **Paula:** *'They make it theirs'*. **Connie:** *'You can always come in'*. **Paula:** *'But we don't want to interrupt your break and don't know it is OK'*.

**R:** 'Families and staff described for a need an additional space where families can be by themselves, to be themselves, have a space that feels like it is theirs, a place to reconnect with themselves or connect with other families going through similar experiences'.

**Liz:** *'Yep. Have a space that feels like it is ours'*. **Paula:** *'Yeah. Somewhere for the families to go when they are having a bad day, like one of Greg's "slumpy" days'*.

.... **R:** 'Do you think families with bedroom residents are less likely to meet other families? They do seem more isolated. Staff thought that one of the advantages of the big dining room was that it was noisy but could help *'to foster the community sort of atmosphere'*? The families who seem know other families tended to be families of dining room residents and they said that they got a lot of support from that'. **Liz:** *'Yes, that makes sense. A lot of the families are there for lunch, they come to feed their family, and it's where you get to meet other people. You talk a lot about the other residents and that's what I feel, you don't know what is going on here. You have to guess. We all want to know what's going on; we don't want secrecy'*. **Meg:** *'I can see how it might feel like that, but it's not intended'*. **R:** 'Do you think the bar design around the nursing home is part of what gives

that impression? Some families said it felt like a barrier'. **Meg:** *Personally, I don't like the bar. The care staff hide behind it when they should be out on the floor with the residents.*

.... **R:** 'When I asked how a care home should feel, the unanimous response was that it should feel welcoming and homely. I think that this suggests that welcome means something more than décor. It is not that staff are not kind to family and residents; it is that people have little sense of belonging or being a part of the care home. One family member said welcoming means *'it should make you want to be there'*. Both staff and family said that the wing *'should feel like home'*, *'it should feel like their space'*, *'it's their home'*. I think feeling in place, that you belong, or you dwell here has a significant impact on a sense of well-being'.

**Angus:** *Maree's problem is that there wasn't a great welcoming thing, not that there needs to be, but something. But she can't accept the fact that this is where she stays "when am I coming home", this is what I get every day. And I say well, when you get better. I tell her they are treating you for dementia and it might take a while. But have they told you when I'm coming home? Every day, I dread it. She just won't accept the fact that this is her home now.*

'So what then, does welcoming mean to you'? **Paula:** *'That's hard'*. **Meg:** *'Does it mean different things to different people'*. **Liz:** *'When I came in the first time, I thought, what is this? The staff are behind it, it looks like a pub, like a pub (laughed)'*. **R:** 'Apparently it was designed to look like a bar'. **Paula:** *'Seriously? Why would they do that?'*

.....**R:** 'Residents said that the best part of their day was when family were here'. **Ben:** *'Yeah, I could believe that'*.

## **APPENDIX 9: Participant descriptions**

Note: All participants have a pseudonym.

## **STAFF PARTICIPANTS**

### **DONNA, physiotherapist**

**Prompted Conversation: 24 June 2015**

Donna was 32 years old and had about 7 years professional experience. She was passionate about her work and well informed about dementia specific needs in both care and the environment. She spoke about her frustration with the way the environment could be improved for the residents, in particular the need for red toilet seats, bright coloured sheets to reduce falls and red dinner plates to improve appetite. She also spoke at length about how the design did not support her work, *'So, not the best but then we've got to work with what we've got. There is nowhere to "walk them" and too many distractions for the residents'*.

Donna worked full time, weekdays 8 am til 4 pm and had worked in other care homes on the site for 5 years prior to commencing in Longleaf.

### **BEN, CSE**

**Prompted Conversation: 26 June 2015**

Ben was from Nepal. Age: 34. He had been at Longleaf since it opened 3 years prior to our conversation. Initially, he worked full time, but had recently reduced his hours to complete a Bachelor of Nursing. Ben was very caring of the residents but seemed a little disenchanted with working in aged care. He initially seemed unable to be critical of the organisation, but towards the end of our conversation, he spoke in detail about how inappropriate he felt it was that residents' bodies are removed through the main living area. *'With the current layout, it is very hard to manage that. We should have an access to manage body removal so that the residents don't see'*.

Ben worked the morning shift on Sundays, Mondays, and Tuesdays. He had worked in another Aged Care Inc. home for a year before being transferred to Longleaf and had worked in aged care for four years.

### **ANNE, CSE/Recreation officer**

**Prompted Conversation: 3 July 2015**

Age: 50. Anne cared for the residents and was quite down to earth. She said that she had received no dementia specific training but felt it wasn't necessary as she had worked in aged care for 20 years.

Anne seemed to find the changing rules and accreditation requirements limiting and unnecessary. She was also quite openly critical of the architects of Longleaf and provided several examples of design oversights. *'This is where they are going to spend the rest of their lives. Well, they probably didn't think about that at the time. It's not designed for that, for sure'*.

Anne has worked with the Aged Care Inc. for over 20 years including the old nursing home that Longleaf replaced. She worked full-time from Monday to Friday, 8 am til 4 pm.

### **CONNIE, CSE**

**Prompted Conversation: 4 and 10 July 2015**

Connie was from Tibet. Her English was fair but that she described it as better than when she first started here, at Aged Care Inc. 7 years ago. Both Connie and Molly spoke at length about the different culture in Australia and their own countries. Connie is caring but said the job was becoming harder. She finds aged care very sad and feels for the residents. It's tough, very tough. Very, very different from my culture. *'But in here [Longleaf], they are not peaceful. They get worried. They say this is not my home'*.

During our conversation, she seemed hesitant to be critical, and worried about *'not being helpful to my study'*. She eventually relaxed and was able to speak more freely in the second part of the conversation. The environment was a useful prompt and helped her to talk in more detail.

Connie had worked in Longleaf since it opened, and for 4 years in the previous nursing home. She worked afternoon shifts Monday to Friday, plus a Saturday evening shift.

**SOPHIE, Student nurse**

**Prompted Conversation: 6 July 2015**

Age: 20. Sophie was studying to be a nurse at university. She was not sure that she would work in aged care once she graduated but said the work was very rewarding. The residents really like her as she is quite attentive and speaks beautifully with them.

She also thought about the family. *'Well, I think they should have an area like this is where families can go, and they can talk with each other.... chill out and... I don't know. Yeah, and that's what I would like if I were in this situation. I'd like if there was a like an area where I could see my relative, whatever, then come here and have a moment for myself if I was getting upset or if I just needed time, then I could go back more composed and stuff.'*

She had worked in aged care for 6 months, in Longleaf. She worked 2 weekday shifts plus weekend relief work. Age:20.

**MOLLY, CSE**

**Prompted Conversation: 12 July 2015**

Age: 29. Molly was a RN in her native country, Nepal but was required to complete further studies in Australia. She was studying Nursing at the time of this study.

She is kindly and cares for the residents. She spoke of finding the cultural differences between Nepal and Australia in attitudes towards institutionalising the dying and older people challenging. *'They have already got so many stigma, like we are in a nursing home.'*

Previously she worked full-time in Longleaf. She had reduced her shifts to 3 mornings a week to study. Molly had worked in aged care for 3 years, all in Longleaf.

**WARREN, CSE**

**Prompted Conversation: 24 July 2015**

Aged: 46. Warren had been working in Longleaf for 2 and a half years following caring for his aunty and needing a career change from hospitality. He works hard and seemed to genuinely like the residents.

He described an RACF he had worked in previously with a specific palliative care room lacking in Longleaf. *'If someone was dying, they had a room where the resident, family member was in the room, bathroom, shower. There was an extra bed there. You can actually sit there and sleep, a fridge, you know. More of a dying room really.'*

Warren is a CSE, he worked full-time weekdays 7 am til 3 pm. He had worked previously for another aged care organisation for 2 years prior to Aged Care Inc.

**JACK, CSE**

**Prompted Conversation: 25 July 2015**

Aged: 33. He has been working at Longleaf for almost years which is the same length of time that he has worked in aged care. Jack was from Nepal. He was quite charming with the residents but spoke of ambitions outside of working in aged care.

Jack had worked in aged care with Aged Care Inc. for 8 years coming to Longleaf when it opened. He worked full-time weekdays 7 am til 3 pm

**LYN: Occupational Therapist****Prompted Conversation: 20 and 25 July 2015**

Age: 62 Lyn had worked for Aged Care Inc. for over 25 years. She was a softly spoken gentlewoman. She loved her job but wished she could do more of the *'little things that make a person's day'*. Like many others, she does her best but feels that life has become too safety conscious at the loss of freedom for both herself in the work she does and for the residents. As an Occupational Therapist, she understands the value in good design, perhaps better than any other staff in the study.

Lyn worked 3 days per week from 9 til 5.30 and came over from the old nursing home to Longleaf.

**JAN, RN****Prompted Conversation: 28 August 2015**

Jan had worked for Aged Care Inc. for 28 years including in the nursing home that Longleaf replaced. She is well into her 60's and had *'seen it all'*. Under the apparently tough exterior, she is passionate about the needs of the residents and misses the old home that she felt had a better sense of community. She recognises that change is normal but that doesn't *'mean that it's always for the better'*. She is distressed and frustrated by the *'all the rules these days'* and believed that it has *'made things worse for the residents.'*

Jan had been the 'in-charge' [Care Manager] in both the nursing home that Longleaf replaced and for the first year of operations of Longleaf. Jan was working three days a week in another wing in Casuarina House at the time of our prompted conversation.

**MEG, EEN****Prompted Conversation: 3 September 2015**

Meg worked varying on-call shifts. She was permanent part-time for 3 days a week but generally worked a five-day week filling in for others. Meg was a cheery soul with a lot of energy. The staff and residents love her. She is dedicated to her job and is sensible, open-minded. Meg genuinely seemed to love the residents, was amused by them, and never became annoyed by what some others call 'behaviours'.

Meg felt that aged care *'had a long way to go'*. *'I won't be going into care. So unnatural, the environment'*.

Meg has 24 years professional nursing experience, four in aged care of which the last 8 months have been in Longleaf.

**CARE MANAGERS****JILL, CARE MANAGER/ DON, Casuarina House****Prompted Conversation: 17 July 2015**

Jill had 45 years of professional nursing experience. She was initially reserved in the recorded conversation, but once we started to speak about her passion which is hospice and palliative care, she relaxed and was far more engaged. Jill was the manager of the whole of Casuarina House which housed 161 residents. She personally knew all of the residents even though she is not *'on the floor'*. She talks fondly about each individual; they are all *'gorgeous'*, or *'very dear'*.

Jill had 6 years specialising in aged care and had worked for Aged Care Inc. for two years at the time of our conversation. Jill was very supportive and helpful in my study engaging staff interest and ensuring they were available for conversations.

Neither Jill, nor the deputy DON, Jackie were working with Aged Care Inc. when Casuarina House had been designed or built.



**JACKIE, Deputy DON, Casuarina House****Prompted Conversation: 15 July 2015**

Jackie had spent the majority of her nursing career in acute care/ intensive care. She described her current position as taking care of the clinical program for Casuarina House. She was very caring of the residents, a compassionate and sensible woman who was supportive of my study.

Jenny has just over 40 years professional experience, mostly in intensive care. She had 2 years of experience specifically in aged care and 8 months as Deputy DON.

**FAMILY PARTICIPANTS****LIZ, Joe's wife****Prompted Conversation: 7 and 18 July 2015**

She was 70. Like Joe, she was Dutch. She was elegant, beautifully spoken and Joe adores her.

Liz told me that Joe had reasonable verbal skills, and that he would be able to tell me in the conversation if he felt uncomfortable and did not want to answer a question.

She had visited 7 days a week, but had recently dropped to 6 days but recognised, *'I need to keep coming. He says I am all he looks forward to'*.

**BRIAN, Elsie's son****Prompted Conversation: 25 July 2015**

Brian was a builder. He spoke about the building design both from a practical construction viewpoint and as the place that his mother resided. We talked at length about the building and while he is careful not to be critical, he talks of Elsie's need for more independence and her loneliness in Longleaf.

He told me that the family have only just recognised that Edna misses her sewing and they bring her mending and sewing to do. If she gets upset during the one-to one, just bring her back by talking about her sewing, *'it's her life'*.

Edna had been living in Longleaf for just over 3 months at the time of the conversation. Edna died before I had the chance to speak with her of a sudden stroke. Brian was quoted in this study, but his and Elsie's story was not told in full.

Brian visited 3 or 4 times a week.

**MEL, Mary's daughter****Prompted Conversation: 28 August 2015**

Mel was a cheerful woman who came from a large family that lived locally. Mel cried for weeks after her mother was placed, as the admission was *'shocking and unexpected'*. Her mother had a major surgery and *'woke up with dementia'*. Mel was one of the most inter-active with other residents and family members in the dining room.

Mary became unwell soon after the conversation with Mel and went to hospital for 2 weeks. She was never as well as prior to her hospital admission and while I waited for an opportunity to talk with her, she continued to decline, was re-admitted several times before dying in hospital.

Mel visited daily from 2 pm until *'after dinner'*.

**KATE, May's daughter****Prompted Conversation: 30 August 2015**

Kate was 67 and May's only living daughter. She was May's guardian and was also caring for her father, May's husband who lived in the family home.

Kate visited daily. She described the shorter visits during the week which she managed around her full-time job commitments as challenging. May was *'repetitive and complaining'*, but the longer weekend visits were *'more meaningful and satisfying'*.

**DENISE, Antonia's daughter**

**Prompted Conversation: 6 September 2015**

Denise was the oldest of Antonia's six children. Five lived locally and co-ordinate with each other so that Antonia has a visitor almost every day. Denise worked in mental health and had a practical but compassionate attitude towards her mother's health. She talked of borrowing from her experiences in her work for mental health well-being, and of what could be applied in Longleaf, *'but nobody here [Longleaf] seems to be thinking about companionship for the residents'*.

Denise lived an hour away from Longleaf and spent a whole day each weekend with her mother. Three or four of her siblings lived closer to Longleaf, and Antonia had a visitor on most days.

**PAULA, Greg's wife**

**Prompted Conversation: 15 September 2015**

Paula was a bubbly woman who related *'working hard to stay positive'*. She cared for Greg for years at home until his disability became too difficult. She cried in the nurses' office every night for the first 3 months but said she was now reconciled and accepting that *'he is never coming home'*. Paula holds out for the good but unpredictable moments when Greg is responsive

Paula visited every day and worried that she might miss out on a good day if she did not. *'The staff said not to come every-day, to have some life outside. But what can you do? It is hard for me, but even harder for him. The good moments are becoming rarer'*.

**KATHY, Jean's daughter**

**Prompted Conversation: 20 September 2015**

Kathy was a counsellor working with teenagers. She was a practical and compassionate woman. Like most of the adult children in the study, she was well into her sixties with adult children and grandchildren of her own. Jean had lived in Kathy's home prior to admission to Longleaf, *'until it became too much. But it still feels wrong that mum is in a nursing home'*.

Kathy visited daily and usually timed her visits around mealtimes *'to give the visit a focus'*.

**ANGUS, Maree's husband**

**Prompted Conversation: 28 November 2015**

Angus was a kindly man who spoke often of his love for his wife. He expressed feeling guilty about being unable to care for her at home but also that she seemed so unhappy in Longleaf. *'All I want is her happiness'*. He was quite frail and walked with a stick.

He encouraged her to come out to the dining room in an attempt to help her meet people as he worried that Mary was lonely.

Angus lived in The Village and visited Maree daily for relatively long visits of five or six hours.

**BERNIE, Tom's wife**

**Prompted Conversation: 2 December 2015**

Bernie was a well-spoken and chatty woman with several health conditions including a neck problem that left her doubled over. She is quite accepting of John's condition and seems to see it as part of ageing and just gets on with life. She is a positive woman and always quite cheerful.

Two of Tom's 4 children live within a reasonable distance of the home and visit regularly. Bernie lived in The Village and visits Tom every day spending several hours a day and most of Sunday.

## **RESIDENTS PARTICIPANTS**

The residents' biographies are provided in more detail in their stories in Chapters, 5, 6, and 7.

**JOE:** Age, 92. Stay in Longleaf at time of prompted conversation: approximately 18 months.

Prompted Conversation: 11 September 2015, Follow-up Conversation: 22 March 2016

**JEAN:** Age, 95. Stay in Longleaf at time of prompted conversation: approximately 10 months.

Prompted Conversation: 4 October 2015, Follow-up Conversation: 30 March 2016

**MARG:** Age, 90. Stay in Longleaf at time of prompted conversation: approximately 13 months.

Prompted Conversation: 5 October 2015, Follow-up Conversation: 21 March 2016

**ANTONIA:** Age, 87, Stay in Longleaf at time of prompted conversation: approximately 22 months.

Prompted Conversation: 9 October 2015, Follow-up Conversation: 30 March 2016

**MAY:** Age, 92, Stay in Longleaf at time of prompted conversation: approximately 5 months.

Prompted Conversation: 17 October 2015, Follow-up Conversation: 22 March 2016

**GREG:** Age, 73, Stay in Longleaf at time of prompted conversation: approximately 9 months.

Prompted Conversation: 19 October 2015, Follow-up Conversation: deemed too unwell

**MAREE:** Age, 85, Stay in Longleaf at time of prompted conversation: approximately 3 months.

Prompted Conversation: 29 November 2015, Follow-up Conversation: 28 March 2016

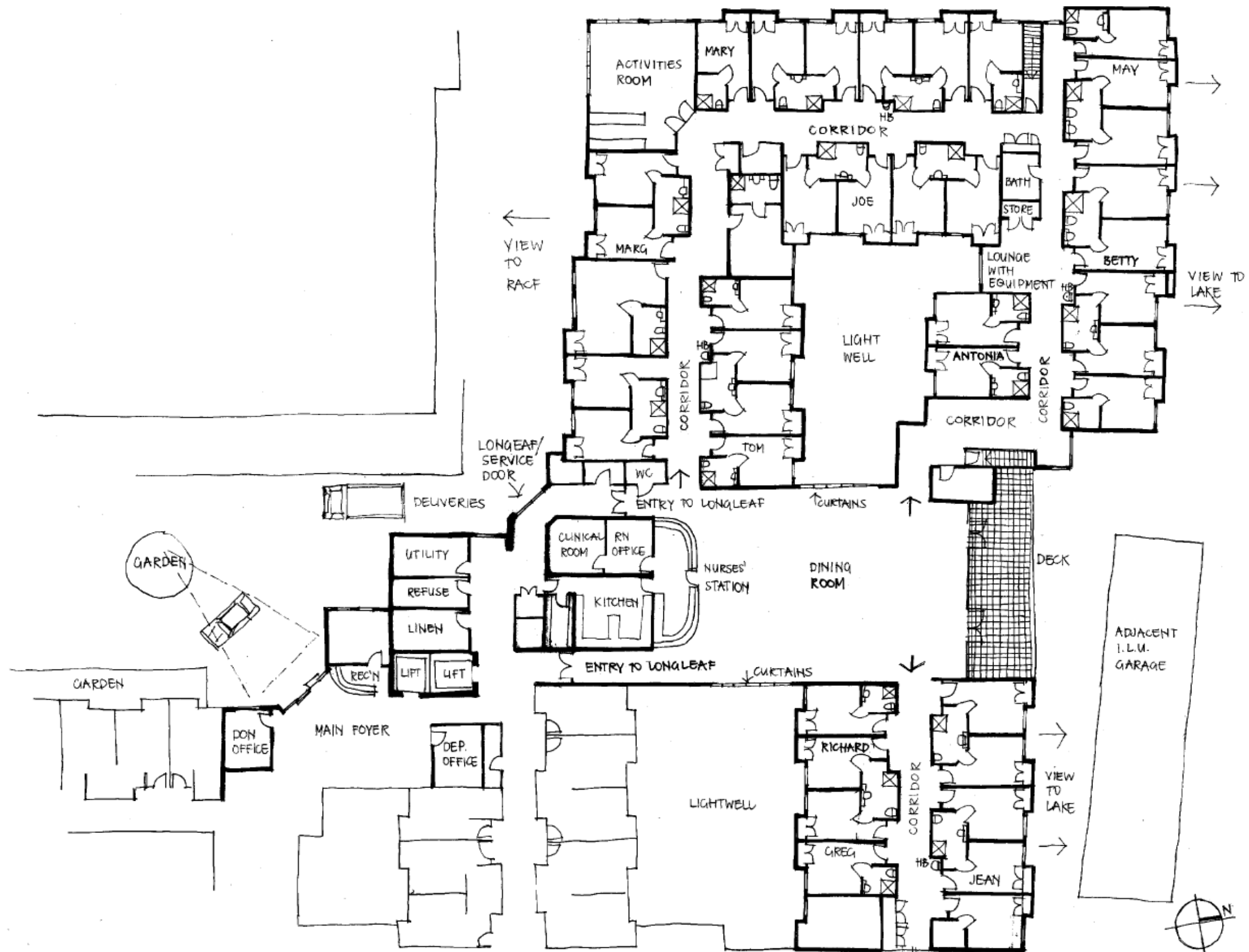
**BETTY:** Age, 88, Stay in Longleaf at time of prompted conversation: approximately 3 months.

Prompted Conversation: 29 November 2015, Follow-up Conversation: 28 March 2016

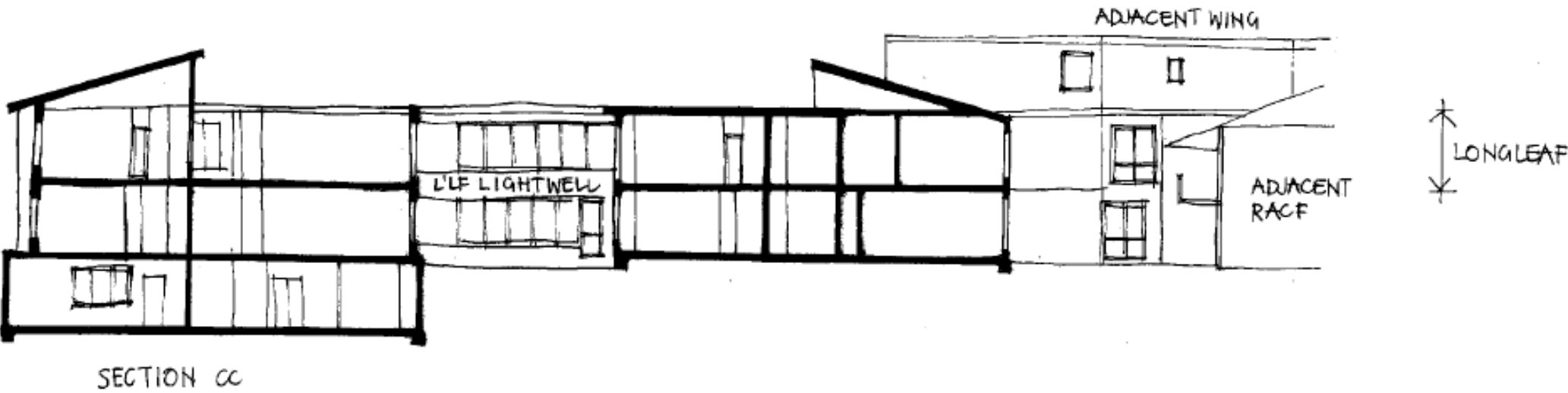
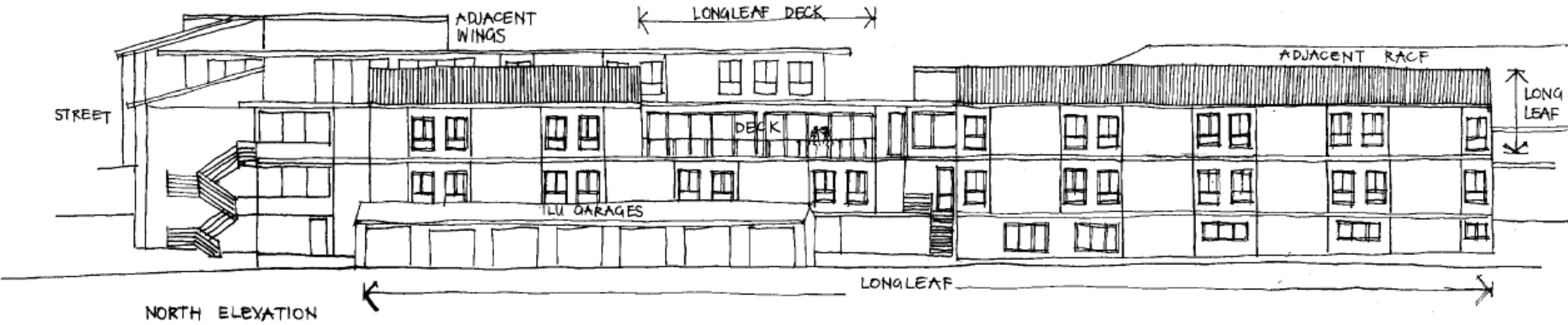
**TOM:** Age, 87, Stay in Longleaf at time of prompted conversation: approximately 2 years.

Conversation: 5 December 2015, Follow-up Conversation: Died 3 weeks after Prompted Conversation

APPENDIX 10: Longleaf floor plans - not to scale



Elevations- not too scale



## **APPENDIX 11 Conference papers**

Kennedy, K 2015 'The architecture of well-being for dementia and ageing in-place: exploring how the design of Australian RACFs can enhance well-being of people living and dying with dementia, their family, and staff carers', *48<sup>th</sup> AAG National Conference*, 4-6 November 2015, Alice Springs, Northern Territory, Australia

Kennedy, K 2017 'Wellbeing and the lived experience of dying with dementia in a typical Australian RACF'. In Seemann, K and Barron, D. (Eds.). 2017. *Design4Health, Melbourne. Proceedings of the Fourth International Conference on Design4Health 2017*, (pp. 115-118) Melbourne Cricket Ground, 4 - 7 Dec 2017, Melbourne, Victoria, Australia: Centre for Design Innovation, Swinburne University of Technology.